A Transplant Patient's Experiences with Communicating with a Donor Family
by Jim Gleason
recovering Heart Transplant Patient (transplanted 10/19/94)

This is one in a series of short articles sharing this heart transplant patient's experiences in some area of common concern. Included in the series are similar articles covering Nutrition, Weight Change, Biopsy, Rejection, Medication, Exercise, Motivation & Boredom, Transplant Surgery, and Fear & Facing Death. These are not meant to replace any professional medical advice, but rather are one layman's interpretations of actual experiences he had while waiting for, undergoing, and finally, recovering from, a heart transplant at the University of PA Medical Center. While each person will have their own unique experiences, many have found this simple sharing to be of value in reducing their own concerns - seeing that such feelings and experiences are part of the normal recovery process - seeing that there is light at the end of what may now appear to be a very dark tunnel through the eyes of another who has passed this way ahead of them - and, most importantly, the light at the end of that tunnel is not a train engine coming directly at them, it is the light of another sunny day, another gift of a day of life. May you find joy in that daily gift of life as I have through the miracle of this medical science known as transplantation.

It’s not easy…
In my favorite transplant love story movie, Return to Me, there is a touching scene dealing with the difficulty many transplant recipients experience in writing that thank you note to their donor family. In this scene, Grace, the heart recipient (played so perfectly by Minnie Driver), is still torturing herself about actually mailing the letter she has written and been carrying around with her since receiving her new heart a year ago. Her sister (with five small kids in tow) offers her the encouragement she finally needs to so tentatively drop that letter into the nearby mailbox there at the zoo (where, coincidently, her donor’s spouse, played by David Duchovny, is working and they come into contact for the first time). This is a beautiful heart transplant story I highly recommend to your own movie viewing pleasure.

(If reading this chapter directly on the CD version of the book, click on this movie title to hear their conversation from that scene and feel what she is going through—→ Return to Me)

A note of what to expect here . . .
This beautiful chapter is different than any other in this book. My own writings are offered mostly only as commentary and as usual, are based on my personal experience and thoughts. The difference is that here my writings are but a very small part of this chapter. Most of what you will read here are the sharings of others on this subject, recipients, family supporters and donor family members who reached out to help with this “project.” Let me explain further.
Back in 1999 when the original idea for this chapter came to me, I reached out and offered an opportunity for families and recipients to share their own experiences to become a part of this special writing. Many responded and with names changed to protect their privacy, I have tried to include many of their e-mails to give you some idea of just how varied the experiences in communicating with their donors have been. In this area there are no simple right or wrong answers or way to do things. There are some guidelines, and beyond the anecdotal opinions shared here, I have even included some formal guidelines that were put together by various organizations to help you. As you will read, I do offer some of my own suggestions, but the main one is to just follow your own heart and trust God in whatever you decide to do, error on the side of reaching out and saying thank you. There are safeguards built into the communications process as you come to learn designed to protect everyone from those concerns you may have.

Besides the simple e-mails quoted here, I had the good fortune to be able to share a few more in-depth stories either from friends I knew personally or from correspondences that evolved in the course of this collecting input. Some share their story of finally meeting their donor families, and in one such case you will read the newspaper articles that even orchestrated and documented that experience.

But beyond such sharings and my comments, there is yet another very special opportunity offered in this chapter that I don’t think you will find anywhere else. As I was putting this chapter together with all the input mentioned above, a very special donor family offered to add their own story, insights and experiences to this writing. They had gone through the tragedy and processes involved with organ donation and even written to their recipients. What feelings went behind this are shared in their story. As that story unfolds, you will gain insight into what it is like to finally communicate and even come face to face with your recipient from a donor family perspective. Even their e-mails of correspondence were preserved and offered for use in this chapter as a way of giving recipients and families the full story by way of encouraging you to write that note of thanks. While again this is just one family’s experience, and know up front that you will read some very different stories in the e-mails of others in the first half of this chapter, it is their true story. If you have not heard from your own donor family, take this story to heart and imagine that it is your own.

I think you will agree after reading this entire chapter that you will have a lot more to build upon in making your own unique donor communication decisions.

Be forewarned, as emotional as some of the earlier chapters have been in this very long book (fast approaching 100 chapters!), you may want to have some tissues handy when you get to the second half of this chapter. It is written from the hearts of some very special people, people like yourself who have experienced life in ways that too few ever will, and in so doing, their stories and sharings hopefully will touch your heart in a way that it will never be the same again. I can tell you that it has mine, in a very unique and positive way. I pray that you will feel the same and take actions accordingly in your own life. With that said, lets get on with this chapter…
About that “Thank you…”

As pointed out in my own story in an earlier chapter, at some point after transplant, if you weren’t aware of it before, you will come to learn how this whole organ transplant process works. Without a donor’s decision there is no organ to transplant. Without an organ being available waiting patients die. As this is being written in 2005, over 87,000 people wait for a life saving organ transplant and about 17 die waiting every day in the United States alone. Stepping aside from the growing numbers of living donors, you come to realize that someone died and either they or their loving family at that moment of tragedy either honored that loved one’s wishes or decided on their own to donate those organs for transplant, offering the gift of life to strangers they have no expectation of ever getting to know or meet. At the other end there is a patient like myself or yourself, laying in a bed, waiting for that life saving gift.

Often patients report feeling guilty waiting for someone to die like this. Hopefully, if you ever had such thoughts, you expressed them to your transplant team and they helped you come to understand that that death is independent of your hoping for a life saving or life enhancing organ transplant. Your donor died and everything that could be done to save them was done. At some point during that tragic experience, your donor family was offered the opportunity to make a decision about donating their loved one’s organs. Maybe they were shown their loved one’s driver’s license with the “Organ Donor” designation on it and asked if they would honor their loved one’s wishes. How much easier it is for that family to know their loved one’s decision instead of having to make it themselves under such sad circumstances. They had no choice about that death but they did have a choice whether to make some good come out of such tragedy.

Over time, and I have heard it over and over again in my many encounters with donor families, this decision is what helps them deal with the grief over that loss. Some even report that giving actually saved their own lives when the loss of their loved one left them with no reason to go on living. If they get involved in a donor family support group, like our local Hearts of GOLD group that volunteer for the Gift of Life Donor Program (our OPO) here in the Philadelphia area, or some similar volunteer organization involving transplant recipients, they will openly share joy in seeing the successful outcome of such decisions when you or others like you demonstrate that life can return back to “normal” post transplant through their decision to donate.
So why is it so hard to sit down and write that thank you letter to a donor family? For many it is hard, especially that first time. You may feel afraid that your note will cause them to be brought back to that time of sorrow. As you heard in that sound bite from the movie in the introduction to this chapter, it is not unusual to feel that any words you write will be inadequate to express the gratitude you feel. You may not be ready to deal with such an expression of emotion until some time has past and your recovery is assured. Many are concerned that if their health isn’t totally restored, their message may be a disappointment, an indication that you, their recipient, haven’t taken good enough care of their loved one’s precious gift. As you read further in this chapter the sharings of so many who contributed to this chapter, you will come to see that all such thoughts and feelings are normal and felt by most transplant patients in one form or another, especially in the highly emotional state we often find ourselves post transplant. First, let me warn/assure you that such strong emotional states, often with tears flowing for no apparent reason (even if you were a non-emotional person before), will probably become a fact of life for you. Nobody seems to really be able to explain why, although most medical staffs attribute it to “the meds” and you can accept that if you like, but for most of us there is much more to it. So just get ready and accept it as another part of the “gift” that comes with the organ itself.

Anyway you look at it, at the right time and not a moment before, you will be moved to finally sit down and pen that thank you letter. If you want some sense of what it is like, check out the movie: RETURN TO ME and watch the scene mentioned in this introduction. In it the heart recipient gives an excellent portrayal of the real-life torment that often is involved in finally mailing that letter. Don’t let it overwhelm you. Think of that gift and what it must mean to make such a decision, and what it means to you to have been the unknown benefactor of that decision. They didn’t know you and you didn’t do anything to deserve their generosity. It was a free will gift to an unknown patient, you! Given that, isn’t a simple note of thanks the very least you or I can do?

Having been blessed with knowing quite a few wonderful donor families personally, I will tell you that many donor families wonder what happened with their gift. When such a letter isn’t forthcoming, they often ask why not. Given the magnitude of their gift they find it hard to understand why even a small thank you note isn’t written. Such a letter, however simple, is often received with tears of joy and a family full of shared excitement as they tell anyone who will listen: “Look! We got a letter from OUR recipient!” They will call their family and friends and even other donors and recipients whom they may know with the long awaited news. If you share some simple facts of your life pre and post transplant, they will share in your joy and sorrow as if you were their own family, for in some ways you really are now a part of their family in a very beautiful way. From their loss, you are giving them some solace and reason to be thankful. Even if you are not doing as well as you may wish at this point, they will feel connected to that as well.

As you will see in the notes offered in this chapter, you may or may not ever hear back from your donor family, just as they may or may not ever hear from you. Even if you do write, it
is done anonymously and typically that letter is passed through your transplant center and then on through the OPO who will provide the safeguard of making sure that family really is ready to hear from you. Either one may end up holding your letter until some day in the future when the family is finally ready to allow such contact (or they may never reach that stage of being ready...), even if only one-way. Knowing this, don’t be upset if you don’t hear back immediately. It sometimes takes many months as you will see for such a note to get passed on, or it may never be delivered for any number of reasons – families do move, for example, and the OPO often has no way of contacting them after such a move. The stories that follow often tell of letters not getting forwarded on, but then years later, one from that annual writing process finally does.

The important message I am offering here is that writing that letter is the right thing to do, no matter how many times you may have to sit down to try to write it before you finally do. Make the message simple or deep. The real message is just: “Thanks!” Write it from your heart and with a prayer. You will not go wrong. God will not let anything coming from your heart with such good intentions hurt your donor family. Trust Him on this.

Let me share a personal note posted by the mother of a young boy who became a donor as she wrote it on the message board of a local heart transplant unit for waiting and post transplant patients to read and understand how as a “donor mom” she felt about such communications:

I’ve been dropping by this site daily just for an update of the patients’ progress. Occasionally I have sent a message to the patients, very careful not to mention the fact that I am a donor family member, in fact the mother of a 13 year old killed while riding a bike just over two years ago. I have heard from some of the recipients, and not from others. I have met one of the kidney recipients. I would just like to give you my feelings regarding acknowledgement from a recipient. My heart soars knowing that my son’s recipient is aware of the gift received, and that his gift was of value. I know it has helped me to make sense of his death that another has a more fulfilled and healthier life. I pray for all recipients that they may find a renewed and healthier life. Please be happy with your new life, and just know what it means to a donor family. Please have a happy and healthy life, and know that you are in my prayers.

...Pam

As for me . . .

Personally, I have found such writing to my donor family very easy, especially with this strong new heart to help me. If you are still having a hard time doing it despite my advice to “keep it simple” as a way to face it, there are other resources out there to help. Contact your local transplant center or OPO and ask them for a brochure they probably have on hand on “how to communicate with your donor family” or some similar title. If they can’t help, I know our local OPO can. Check their web site at www.donors1.org and use that contact to ask them for a copy.

What follows are those e-mails of donor communications sharings I promised. Each writer offers their own unique view based on their own situation and experience. Don’t expect
simple answers. In the end it will still be up to you to do what your heart tells you is right. Follow your heart and don’t feel guilt about whatever path that decision takes you.

My original request as posted in 1999 . . .

Subject: Donor Communications
Date: 8/15/99
To: TRNSPLNT@WUVMD.WUSTL.EDU
From: Jim Gleason

At a recent gathering of donor families the discussion of hearing from the recipients of their loved ones' donated organs was held. It was the general consensus that everyone wanted to hear how "their" recipients were doing - anonymously or even in direct contact. It was surprising to hear their very strong feelings about not having heard anything from the recipients (almost always the case - they had no communications at all - some only the initial general feedback from the OPO and many not even that...).

As a recipient, I felt privileged to be allowed this direct insight, but very guilty on behalf of recipients in general that we have left these families without such messages of gratitude and feedback. Many of these families had gone through very emotional experiences and desperately wanted to know that something good had come from this very difficult decision. Many could not understand why nobody said even a simple thank you - even in cases where many organs had been donated and they never heard from a single one!

I know how difficult such writing is not only from my own annual letter writing, but also from discussion with many recipients over these past years - many who just can't bring themselves to write and others who haven't written for many other reasons. Even the many who do write find it filled with emotion and concern for the welfare of the donor family and for the "correctness" of the message they are trying to express.

I shared with those families some of the many reasons recipients I know have not written. They were surprised. Many had never even met a recipient personally no less heard from one on this issue. I offered them a personal (and tear-filled) message of thanks on behalf of recipients everywhere who were not so fortunate as I was in being there to hear and respond with such insights and that message that we all feel.

Reflecting on this experience, I came up with an idea that you can help with.

This donor group, in conjunction with a related recipient group, will be developing a booklet of guidelines for donor/recipient communications (not aimed at direct contact, but still at the...
normal anonymous communications that is possible for all...) along with some attempt at understanding the issues that prevent such communications - even some sample letters to encourage writing by example.

Here's where you come in...
I would like to collect insights and experiences from you relative to this subject. Whether you have or have not written to your donor/recipient... For those who haven't (or know of others who haven't) - what are the reasons why not? Good or bad reasons - why not - given the amazing gift you received, at least to say just "Thanks!" What got in the way of your writing?

If you did write - how long after your transplant did you write? Why did you (finally ...) write? How did it feel? What response - if any - did you get (from the OPO, hospital, or receiving family)? If you would care to share that letter for possible inclusion in this planned booklet, and possible inclusion in my own book in a planned chapter on that subject, that would be welcome too, but certainly not necessary....

Anything else you can think of that would fit such a brochure/chapter to help understanding of the issues involved - from either side - would be most welcome.

Along with such a brochure/chapter, I expect to approach TRANSWEB and some other transplant related web sites to possibly host this brochure/chapter. Maybe adding a place to post such real letters for donors/recipient to read who have not heard from their own - so those who haven't heard can "feel" or think these letters could be from their own who couldn't get through to them?

Anyway, that is my idea.... sharing it with you first - for reaction - for suggestions - for input of content. Sharing your response to this request via the transplant newsgroup would be optional, but I'm sure many would benefit from such sharing if you care to do it that way.

Will you help us in developing a solution to this problem with your personal response? Just send it to gleasonjim@aol.com. This is intended to be a confidential response and actual names will not be used nor distributed. I will post updates as this (hopefully) develops. Lets make a difference ..... 

- Jim Gleason (heart recipient 10/19/94)
And the sharings that came back in response...

Subj: Did I contact my donors family?
Date: 8/15/99 1:31:35 PM Eastern Daylight Time
From: liver recipient
To: gleasonjim@aol.com

Dear Jim,
Yes I contacted my donor’s family through the Calif. Transplant Donor Network in San Francisco. Address in case you ever need is 55 Francisco St., Suite 510, San Francisco, Ca. 94133. I sent them a letter at 3 mos out of TX. I never heard from the Donor network or the family. I told them I was doing very well and waited sending them a letter for 3 mos so I could let them know that things look good for the future. So in this case I got no reply. I’m leaving for vacation to see grandbabies for 2 weeks so if you need another reply from me I wont be here. Hope this helps your survey.
Sincerely,
Tx 11/27/98 Calif Pacific Med Ctr. (liver)

Subj: Re: [TRNSPLNT] Donor Communications
Date: 8/15/99 2:04:46 PM Eastern Daylight Time
From: two time kidney recipient and donor family member
To: GleasonJim

Jim,
I think this is wonderful idea! I know I could use some help in forming my letters of thanks. I wrote at the 6 month date, 1 year and again this month for my 2nd year post transplant. (8-31-97-kidney) I was thinking that I might wait a few years for the next letter but I know I won't do that. I'll write yearly. I haven't heard if the OPO even got my letters or if they sent them on. I don't know if they are wanted or an intrusion for this family. I have a hard time trying to say what I feel but the fact that I'm not the "poster child" for transplantation makes it even harder. I've had a lot of problems post tx this time (it's my 2nd tx-first was a living donor). I am unable to walk without pain and I've not been able to return to work or live the life I had hoped so much for. But I'm grateful that I have the ability to try to fight all these things and still have hope for a better tomorrow. I just don't want to tell the donor family that I'm not doing all that well---it's not their problem. They gave me a chance and fate just didn't see it that way. I'm also a donor "family". My best friend died without family near and I was the one to give the OK for tissue and bone and corneas to be donated. I know how hard that is at the time, even being a tx person myself, I had to stop and reason with myself. I have never heard from anyone, even the OPO, about any possible txs done or help given by this gift. My friend’s sister (in another country) would love to hear something also.
Hope this helps with your project.

Subj: Re: Donor Communications
Date: 8/15/99 3:21:34 PM Eastern Daylight Time  
From: a very special heart recipient friend in Fla  
To: GleasonJim@aol.com  

Dear Jim,

I think it is a good idea. I’ll co-operate any way I can and if you need any help, count me in. I can give you my personal experience for whatever it’s worth.

When I returned home from the hospital after the transplant (6 weeks later), I wrote the donor family. (had no idea whether this 23 year old female was single, married or what?) I was told to address it to the donor family and refer to the donor as "your loved one". It was a difficult letter to write inasmuch I was filled with so much emotion: gratitude for the gift of life, yet I wasn't sure how my letter would be received. Would this be too painful for them or a "him"? I discussed his with my coordinator and was encouraged to write. So I did. I expressed my gratitude also my feelings of sorrow for their loss. It was a terrible ordeal for me and I cried and cried while writing it, and again afterwards in reading it over. (Of course the high amounts of immunosuppressive medicines made me more emotional also). The following year I sent another letter and I think in between also. Two years later (after transplant), I received a letter from the mother of the donor, telling me she wanted to write many times before, but when she started, nothing seemed right, so she tore the letter up and didn’t. This time, she was able to put her feelings on paper. She expressed her thanks for my many letters and told me that at very difficult times and when she got blue, she took them out and re-read them. I felt so good hearing from her. I know that all she knew about me was that I had been a bookkeeper and had 4 children. I don’t think they told her my age because I got the impression she thought I had young children. When I wrote back, I mentioned the fact that my 1st grandchild was 4 months old when I had the surgery and that before than I didn’t even know if I would live to see him grow up and develop. Even now, Jim, as I’m writing this, I am crying.

I did say we left the north and moved to Fla. and she wrote back that her father goes to Sarasota in the winter. She requested that I tell her a little about myself - my interests, hobbies etc. and said she made a New Year’s promise to herself to write more often. I think I had 3 letters from her (I saved them as well as mine to her). When I wrote back, still trying to keep things in a general category, I told her I liked to sew, do craft works, play the piano keyboard although I’m not good at it, and love music and that I played mahjong and was active in Bnai Brith. I never got another letter back. I followed it up with holiday cards once in a while and even 2 years ago in Florida, we went to a function in which donor families had made a quilt to memorialize their loved ones and it was a dedication ceremony and very impressive. Transplant recipients were invited to come and I sent her a copy of the dedication program and again expressed my thanks and sorrow to her. I just forwarded the Celebration of Life certificate from my party and a copy of my speech in which I dedicated the evening to her and expressed my thanks to the family again. I would believe that if she were not living, or if these letters could not be forwarded to her, the coordinator would have advised me not to send any more correspondence or would have returned my letters. I don’t know what to think and actually, my writing had discontinued for a while and I skipped the “anniversary” letter for a few years. I can’t help wondering if the religious affiliation might have something to do with it. What are your thoughts on this? (if you have any). I do encourage transplants to write, but still feel that it is best not to know or meet the donor family.
The advice of the coordinators to remain anonymous, I feel, is good advice, and all correspondence that we do is done through the transplant coordinator and is screened because the envelope containing the letter is not sealed.

I hope this hasn’t been too lengthy, but I felt it important to tell you of my experience. I will probably continue to write annually but I’m really not sure how the letters are received at this point.

Take care, Jim...

In an update she sent for this chapter in 2005, she now writes:

To Jim
Date: May 2, 2005
From "a special heart recipient lady friend from Fla"

Just finished reading your newest chapter of your book. Through sobs and tears, I read all of it (including re-reading my own letter). Wow! Such emotional stories!! Surely this should open the doors of communication between donors and recipients! Just keep the kleenex handy!

When we returned from Minneapolis, I tried to contact my donor mom again through the coordinator. I had kept on sending letters through the coordinator (as per your advice) but never heard from her again. Upon calling Hartford Hospital, I told them I wondered if she was still alive, whether she got the letters and if she'd like to hear from me. They researched it and found that she had moved but they were able to locate her and she seemed interested. They told her I'd love to be able to exchange identities and they asked me to send her another note through them and that she would have to sign certain forms in order for us to do so. They felt she wanted to do so. I sent the letter to the coordinators and followed it up a few weeks later but they said she didn't want to go along with it. She didn't even send any sort of reply, so that was that! I was disappointed but at least I made another last attempt. All the conversations with the recipients and donors who were able to meet or bond with one another that we met in Minneapolis were so inspiring that I had high hopes.

Hope all is well with you. Glad you've been inspired to add more chapters to your wonderful book. Makes for beneficial and inspirational reading as always.

Heartfully,
Your heart transplant senior in Fla
PS: See you at the next 2006 Games in Kentucky

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Subj: Re: [TRNSPLNT] Donor Communications
Date: 8/15/99 3:23:28 PM Eastern Daylight Time
From: female recipient
To: GleasonJim@aol.com@WUVMD.WUSTL.EDU

Jim,

A Transplant Patient’s Experiences with Communicating with a Donor Family
Wow! That was a long one. Anyway, my sister wrote a thank you letter to my donor’s family before I was released from ICU. I wrote a thank you card, I believe, about a month or so afterward. I wrote a second thank you card at one year. Why did I stop?

1. I did not receive anything back and kind of felt like I was writing to Santa Claus. How do I know my transplant team forwarded my letters to them?
2. Since I did not hear back I did not know if they were welcome or dreaded. Welcome because someone else was remembering their son and what he ultimately did or dreaded because it reminded them of his terrible, I think violent, death.
3. I really do not want to meet them. I don’t know what that would do for either of us. For me, that would just be too emotional.

After you message I feel maybe I should write another letter. I might discuss it with my transplant coordinator, who is about my 5th one by the way. But like I said, I do not want to meet them. I do not want an extended family. I know I will feel guilty but should not and this is just too emotional for me.

I hope I helped in your survey.

Sincerely,
- grateful recipient

Isn't it Great to be alive!

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I caught your posting on TRNSPLNT, and thought this might be helpful (if you haven't already seen it). This is a guide that Transplant America put together, they also have a guide for the donors family on writing to the transplantee.

Take care.
- thankful recipient

http://members.aol.com/sunsmiled/donorletter.html

At that site is the following guide:

The decision to write to the donor family is a very personal one.

Sometimes, transplant recipients choose to write to donor families to express their gratitude. In response, many donor families have said a card or a personal note from the recipient offers some comfort. Whether or not you decide to write to the donor family - it's your choice.

If you would like to write to the donor family, here is some information you may want to include.

**Talk about yourself:**
- include your first name only
- state in which you live (not the city)
- your job or occupation
- your family situation such as marital status, children, etc.
- your hobbies or interests

**Use Caution:**
- since the religion of the donor's family is unknown, please consider this if you are thinking about including religious comments
- avoid "naming" your transplanted organ

**Talk about your transplant experience:**
- use simple language
- recognize the donor family and thank them for the gift
- describe how long you waited for a transplant (What was the wait like for you and your family?)
- explain how the transplant has improved your health and changed your life (Can you participate in activities now that you couldn't before your transplant?)
- explain what has happened in your life since your transplant
Closing your card or letter:
- sign your first name only
- do not reveal your address, city, or phone number
- do not reveal the name or location of the hospital or your physician

Mailing your card or letter:
Send it to your transplant recipient coordinator at the transplant center. The transplant center will forward it to the appropriate organization. This step allows review of your letter to ensure confidentiality and then your letter will be mailed on to the donor family.

1) Place your card or letter in an unsealed envelope.
2) Include a separate piece of paper with your full name and date of transplant.
3) Place these items in another envelope and mail them to your transplant center.
Allow extra time:
Since your card or letter must be mailed to the transplant center first, and then forwarded on for review, please allow extra time for it to reach the donor family. It may take a few weeks (or longer) after you’ve mailed it for the donor family to receive it.

Will I hear from the donor family?
You may or may not hear from them. Some donor families have said that writing about their loved one and their decision to donate helps them in their grieving process. Other donor families, even though they are comfortable with their decision to donate, prefer privacy and choose not to write to the transplant recipients.

Remember, the donor's family may still be coping with the loss of their loved one and individuals manage grief in different ways. While you may be celebrating the anniversary of receiving your transplant, it is also the anniversary of someone else's loss.

Please ... communicate in a sensitive manner.
Credit: 1993 LifeSource, Upper Midwest Organ Procurement Organization, Inc.
I did write my donor family about 2 to 3 months after the transplant. Having worked in hospitals and in emergency medical settings I was aware of the wrenching pain the decision of donation involves and wanted to try and ease the pain of the family. I also was just so overjoyed at how well I felt I wanted to do something. I also know that the motivation behind most donors (at least what I heard over and over working in an ER) is that "at least he/she will live on in someone else" and..."that way not all of him/her is gone." I wanted to tell the family that as far as I am concerned that is true. For as long as I live, I will remember my donor everyday.

I know the letter was delivered as the organ bank told me it was sent and not returned. I have not had a reply. Unfortunately I cannot send you a copy of the letter. I had a computer problem and the program I used to type it was lost. I could try and recreate it if you would want an approximate letter and not the original.

Subj: Donor Communications
Date: 8/15/99 4:13:14 PM Eastern Daylight Time
From: male recipient from the UK
To: gleasonjim@aol.com

Hello Jim,

I read about your experience at a donor family gathering. Can you give me more details regarding the gathering ie where, when, why etc. Their feelings and lack of letters is the same the world over. Recipients need to respond urgently to this criticism. With the increasing number of donor families the public are picking up on their dissatisfaction, which in turn deters people from wishing to be potential donors!!

Are you aware of the National Donor Family Council (www.kidney.org/recips/donor/)? Some of the points you raise have been addressed by this Council!

Still the more the better.

Regards

- UK recipient

(Note: the answer to his question is that that gathering was a local donor family volunteer organization, Hearts of GOLD, associated with our OPO, the Gift of Life Donor Program here in the Philadelphia area. You can find more about that donor group at the OPO web site: www.donors1.org)
Subj: Donor communications experience
Date: 8/15/99 6:03:53 PM Eastern Daylight Time
From: male heart recipient
To: gleasonjim@aol.com

Jim,

I am glad to hear of such a project and would like to share my experience with you.

My donor communication experience was not at all positive, and I believe I can suggest ways in which the problems I encountered might have been avoided.

I wrote my donor's family less than a year after my heart transplant. The letter was an outpouring of gratitude and thanks for their decision in a very difficult time. It was meant to be anonymous and included no names or identifying characteristics beyond my age and the fact that I had only been married for 18 months when the need for my transplant was discovered.

My donor family never received my letter.

To this day I do not know at what point it was dropped in the trash, although based on some of the attitudes I encountered at my transplant center I have suspicions. In any case, I did not know this, and took their silence as an indication that they were not interested in further anonymous communication (as I offered in my letter).

Five years later, I decided to write another letter to let them know that I was still around and kicking, and that my wife and I had our first child four years after my surgery. Based on suggestions and experiences on the transplant mailing list, I told them I was willing to communicate directly, and that the transplant coordinator could facilitate this. This proved to be a terrible mistake.

The coordinator gave the donor's mother my letter, and verified her contact information. I received a letter from the donor's mother, and we agreed to a telephone conversation. I called her house and the donor's father answered. He was very curt with me after I identified myself, said his wife was out and that he'd tell her I called but wouldn't promise anything.

It was then I discovered that the donor's family was severely dysfunctional. The mother had never told her husband she had been contacted by me - in fact, she later told me that he had never spoken of his daughter's death since it happened. He had never mentioned his daughter again, according to her, either to speak of her life or of her death. My donor left behind a teenage daughter who was also a single teenage mother. The donor had been killed violently by her boyfriend. All of the donor's mother's letters were filled with talk of the murder of her daughter, in graphic detail, of her boyfriend's light sentence, and how she cried all the time for her lost child (her daughter was 33).

After a few attempts to respond, I realized that the depth of this woman's grief and depression were beyond me. I stopped returning her letters. I cannot escape from the guilt about it to this day, although I don't think about it as much as I used to.
Not all donor family contact situations are positive. They can be very bad for the recipient, and reopen or enlarge old wounds for the donor family. I wish I had been given better counsel on this before agreeing to direct communication.

I cannot stress in strong enough terms the importance of a period of anonymous correspondence facilitated by the OPO or transplant program. No matter how "normal" the donor family seems, they might have scars that are not healing and that direct contact will not help. I think it would also be highly advisable for the transplant psychologist to meet with the donor family BEFORE allowing or recommending direct contact. Both of these steps would have saved my wife and I much anguish, grief, and guilt over a situation we did not cause and could not fix, but to which we were inexorably tied as a result of a gesture of kindness. We remain grateful, but at a complete loss as to how to achieve closure on the situation. In all likelihood, we never will.

heart tx 1993

(Jim’s note: in the early 1990’s – and to some degree even today, it was the opinion of medical professionals and some OPO staff, that communications between recipients and donor families was not to be allowed, for the safety of all involved. This example supported that position. Over the years since then this position has changed dramatically. Today, the movement is to support and even encourage such communications and also face to face meetings where both parties indicate their agreement. This practice is often done very carefully with professional counselors from the OPO – although the levels of such professional support being offered varies widely – facilitating the initial contacts and meeting which hopefully today would have avoided the issues described by the writer above. Keep in mind this is still evolving issue so it is not unusual to encounter resistance to such communications and contact, both at the hospital transplant center staff level and the OPO. Also realize that it is the OPO that has the donor contact information, and if the donation did not occur in the same OPO region as the recipient’s transplant hospital, that local OPO would not have been involved. It would be the OPO where the actual donation took place, and while most donations are offered to local patients first, there are a lot of circumstances where the organs will move outside the OPO’s region. There are 58 such regions in the US, by way of example, and they are not aligned with state boundaries in many cases. Note the opposition mentioned from 1991 in the sharing that follows, and how that evolved to encouragement today…)
Subj: RE: [TRNSPLNT] Donor Communications  
Date: 8/15/99 6:09:12 PM Eastern Daylight Time  
From: male recipient MD  
To: GleasonJim@aol.com  

Jim,  
I must admit I have not written to my donor family. At the time of my transplant, November 1991, my transplant center was generally opposed to it. I have thought of writing several years after when people were encouraging it but thought I would be just stirring up some bad memories for my donor family. Still do not know what to do.  
I would be glad to see if we could host such a brochure on our site [www.giftoflife-sc.org]. The only problem would be how much space it would take. Let me know and I will ask our webmaster who is very generous to our cause.  

Regards,  

Jim,  
I was just corresponding with a friend who received a new kidney three weeks ago about this very subject. I told him I thought it was terrible that so many recipients do not write their donor family to thank them for their gift. I think your idea is a very good one since it probably will increase the number of letters written, a very admirable cause. The thoughts you requested follow, as well as my letter, which I have already shared with the Transplant group.  

I knew long before I was called for my transplant that I would write a letter of appreciation. I knew I would feel great gratitude (which I did), and that most donor families do indeed want to hear from the recipients. Also, I thought I owed the family that much. It was an obligation, as well as a want-to-do. All transplant centers and OPOs encourage patients to write. I think my letter pretty much speaks for itself as to why I wrote.  

My transplant was on July 23, 1998. I sent the letter through my transplant team in early January 1999, about a 5 1/2 month period, although I worked on it for a few weeks prior to that in order to get it as "right" as I thought I could. The transplant coordinator confirmed that the letter was delivered by the OPO. I have no reason to doubt her, except that I have had no response. By writing my letter, I felt I had done a very good thing, but, I am a little disappointed I have heard nothing back. However, so be it.  

Maybe the donor families should be encouraged to write back.  

Since you say the donor families also like to hear about how the recipients are doing, since it has been just a little over a year since my donor family was so kind in their time of sorrow, I think I might compose a "progress report" for them. After all, it really must have been a tough decision for the family to make at a very difficult time.
If you have any specific questions, other than what were in your post, feel free to send them along. My letter follows, and I would be very proud to see it included as an example to be used by others to help them write their letters. You might notice I did not refer to the family's very generous gift as "the gift of life." With a kidney, I do not believe it is. It is the gift of a much better life style than what otherwise would have been possible.

Ken (home of Sydney the kidney)

(Note: this was an eye opener for me when he referred to his “gift” as life enhancing rather than a “gift of life” as is so often said. In the case of most kidney patients, there is the alternative of dialysis to maintaining life. The transplant allows them to come off dialysis and that is what he means in saying “life enhancing,” an insight I find very interesting, being a heart recipient myself. Based on my experience I had only thought of transplants as truly “life saving gifts.” Despite this distinction, I can assure you the gratitude of a kidney recipient is no less than from any other organ recipient.

Ken’s letter to the donor family follows:)

==========================================================================

Ken writes:

To the family that enabled my new life,

Although words are not sufficient to express my true feelings and gratitude, please know that I am overwhelmed and still in awe of the miracle of my new kidney. Please accept my heartfelt sympathy for the loss of your loving and very dear family member whose life gift of a new kidney has given me a new beginning, a new life.

I was diagnosed with kidney disease almost five years ago. I have been very proactive researching chronic kidney disease and following doctor’s orders, which I know helped slow the decline of my failing kidneys. I was but one of several fortunate patients who benefited from your selfless decision to help others at a very difficult time. In my case, I feel especially blessed, for I received your gift just weeks before I was to begin dialysis. For this I am, and forever will be, grateful.

I am a 51 year old professional, married man whose life began anew with the addition of the kidney you made possible. In fact, I celebrated my 51st birthday shortly after the transplant operation. Before the transplant, with my own kidneys rapidly losing their ability to function, I had little energy or stamina, and was very limited in the amount of activity I could undertake.
Now, however, I feel like a new person. It has been so long since I have been this well that I can’t recall having felt this good before. With a gradual decline in kidney function, as mine was, the body and mind simply adjust. I thought I felt fine, but knew I was not. Now I feel great, and know that I am!

I am very proud to be able to have your loved one’s kidney functioning within me, and will do everything I can to ensure it will have a long, healthy life. No one could comply more with doctor’s orders, or be more attentive to the needs of a new kidney, than I. My health (except for my failing kidneys) was excellent before the transplant, and now my health is excellent again. A better home for this kidney could not have been found.

Again, thank you so very much for making my new life possible.

- Ken

Subj: expressing thanks to donor families
Date: 8/16/99 12:11:54 AM Eastern Daylight Time
From: female kidney recipient
To: gleasonjim@aol.com

Hi Jim:
I am a kidney transplant recipient of 2 years. It’s been a true blessing in my life. I wrote my donor family 6 months after transplant. It was not easy and I did worry about hurting their feelings, reminding them of the death of the loved one, re-opening the wound which was hopefully healing. I was totally thrilled when they wrote back via BC. Transplant Society. It was a simple typed letter, expressing relief, that I was doing well and appreciated the gift of life. They also wrote, that I must be a very special person (I put an extra care into writing a very special card, stickers, etc. and mentioned that I am praying for them) and that the donor was a very special person too. Of course that brought tears to my eyes. Yes, this is a great dilemma of life and death. I sent X-mas card last Christmas, but I have not heard from them since. Sometimes I wonder, if both sides show interest whether it would be a good idea to meet and thank them personally. Hard to know. Is anyone in regular touch with their donor family? Please let us know.

Regards
- thankful recipient
Subj: Re: [TRNSPLNT] Donor Communications
Date: 8/17/99 12:24:30 AM Eastern Daylight Time
From: living kidney recipient mom
To: GleasonJim

Dear Jim,

Your message made me realize how very lucky I really am. I thank my donor every time I see him and also tell him how much I love him. You see, my donor is my son. And that is what makes me lucky. He has lifted a death sentence from me and he can see the results.

I just can’t imagine anyone not thanking their donor’s family for this same gift I received. Even if they never hear back from the family, at least the family knows that their generous gift did make a big difference in someone’s life. It is a small price to pay for the large gift they received.

Peace to all,
Living donor kidney recipient from Phoenix
Kidney tx 10/15/98

(Note: TRIO is an international organization supporting the transplant community for which this contributor is a long time active leader...)

Subj: Donor letter
Date: 8/16/99 12:38:55 PM Eastern Daylight Time
From: male recipient
To: gleasonjm@aol.com

Wrote my donor family approximately three years after transplant. Received no reply. Plan to write on 7th anniversary. Transplant center didn't encourage contact when I had transplant but has changed tune. Trio has booklet on letters written to donor families and letters written to transplant recipients as follows:

I. Guidelines for Communication Between Donor Families and Transplant Recipients Unveiled

(Minneapolis, MN)- July 27, 1997 -- Responding to the need expressed by donor families and recipients of organ and tissue transplants to receive information about, and communicate with one another, a task force comprised of major national transplant organizations has created guidelines for communication between the two groups. The guidelines will be unveiled today at the annual meeting of the North American Transplant Coordinators Organization in Minneapolis, Minnesota.

The guidelines are based upon the belief that donor families and recipients have the right to choose whether they wish to communicate with each other, and health care professionals are in a position to make these opportunities available to both parties.
Until recently, when donor families and transplant recipients began challenging the status quo, there was inconsistent follow-up with families after donation and many health care professionals believed that donor families and recipients should not communicate with each other. "Not only did this leave the involved parties unfulfilled, we found that sometimes it discouraged organ donations. Families who received little or no information about the recipients of their loved one’s organs were less likely to donate again or recommend it to others, and sometimes, even actively campaigned against organ donation.

The guidelines are intended to provide transplant and procurement professionals with basic systems for providing information to donor families and transplant recipients and establishing methods of communication. The document also includes guides for both donor families and recipients on appropriate written communications to the other party.

Key Guidelines Include the Following:

- At the time of consent to donation, health care professionals should offer an opportunity to donor families and transplant candidates to receive follow-up information about the donor or recipient at a designated time after transplantation.

- Special attention should be paid to the wishes of those who do not want to receive such follow-up information. They should be assured that all personal information will be kept confidential.

- Donor families and recipients who do not wish to receive information should be informed by health care professionals that they can change their decision on this matter and obtain additional information at any time in the future. Within one month of donation, health care professionals should provide donor families and recipients who wish to receive it, a written report confirming which organs and tissues were procured and information on age, gender, geographical region, occupation and family information, along with cause of death or illness.

- If the intended recipient is unwilling to accept written communication, health care professionals should retain it in their files and inform authors that their communication has not been forwarded for this reason.

- If members of donor families and transplant recipients wish to disclose their names and/or addresses in order to communicate directly via phone, e-mail or in person, that disclosure should be accomplished by mutual agreement of both parties. Direct communication should take place without the assistance of the health care professionals, unless they are wanted by the participants.

The guidelines will be distributed by mail and in person via paired teams of donor families and recipients to transplant physicians, surgeons, social workers, procurement coordinators, clinical coordinators and critical care nurses.

Copies of the guidelines can also be obtained by calling TRIO, 1-800-TRIO-386 (or visit their web site at http://www.trioweb.org/)
The communications guidelines were developed as a result of a collaborative effort among the following national transplant-related organizations: The National Kidney Foundation's National Donor Family Council, the American Association of Tissue Banks, the American Red Cross Tissue Services, the American Association of Critical Care Nurses, the Musculoskeletal Transplant Foundation, the North American Transplant Coordinators Organization, United Network for Organ Sharing, Eye Bank Association of America, American Society of Minority Health and Transplant Professionals, Transplant Recipients International Organization, U.S. Health and Human Services' Division of Transplantation and the Association of Organ Procurement Organizations.

The guidelines are based on research conducted with transplant recipients/candidates, donor families, clinical transplant coordinators and organ procurement coordinators to determine current practice and necessary improvements. The draft document was circulated for review and public comment for a one-year period.

4/23/2005:
In a message dated 4/24/2005
Hi Jim
I know you and have seen you at some of the general Second Chance meetings. I have a heart and kidney tx. in 1993 at Hahnemann Hospital (Philadelphia, PA). I wrote to my donor’s family 3 yrs before I heard from them. I knew my donor was a 17 yr. old boy. I last letter I wrote I asked them to tell me about their son (his parents donated many of Jeff's organs). I finally heard from them (I understood why I didn’t hear sooner) but I savored that letter. The mom wrote it and she told me about Jeff and the family. I have thought of them many times but was sick and in bad shape quite a few times. I am a little better and I want to write to them again to let them know I am still around. I don’t know if they heard from the other recipients or not.
I hope you can use this for your book. Do you need names?
I read part of something you were writing a couple of years ago.
Thanks Jim,
- grateful heart AND kidney recipient from Hahnemann Hospital

(Note: the following note is from a long time friend who obviously was a pioneer, active in the transplant community from its early days. I am proud to preserve her thoughts here since sadly we lost Joanne a few years ago, but her presence will always be felt in my heart. Read as she shares not only the evolution in attitude towards donor communications since those early 1970’s, but also her concerns with having had multiple transplants and how the loss of those organs affected her thinking about reaching out to her donors…)

Subj: Re: Donor Communications
Date: 8/16/99
From: Kidney04

Jim,

What a wonderful idea! I have to confess, I have never contact my donor family. Here is my lame excuse. When I was transplanted back in 1974 it wasn't an option, of course I received my dad's precious kidney, so a letter of appreciation to a stranger wasn't necessary. I'm not sure when programs with donor families were started, but I do know that when I had my second and third transplants, writing to my donor family was NEVER encouraged! When I had my fourth transplant, yes I knew about the changes with attitudes regarding contact with donor families, but I wasn't open to the idea. And I'll tell you why. In 1992 my life was in shambles, my husband left, my daughter was 350 miles away at college, and going through yet another transplant was overwhelming! When I started to get involved with the transplant games, my first was Atlanta, did I realize that I had an obligation to my donor family. Not that I never thought about them. I pray for them, and sometimes I make decisions with the knowledge, gratitude, and love for my families! For instance, I will take on a challenge to live my life with zest and enthusiasm because if it wasn't for a stranger to make that most difficult decision to donate, I would have NEVER have had the opportunity to take on the world! Like having bubbles in my car!!!!!

Yes, I did contact KIDNEY1 (our local OPO - Jim’s note: today this is known as the Gift of Life Donor Program) about writing a letter, but I never followed through. Here is my dilemma. I would never want my donor family to know that I had 4 transplants because I would think that the family would have another lost of their love one, if I told them, "thank you, but I rejected your love one's kidney!" I just couldn't do it! I would feel guilty. I would think that the donor family would doubt their decision or that I wasn't a compliant patient.

It blows my mind over the years meeting and talking to donor families. I have even discussed with several families about my feelings about writing to my families after all these years. I received mixed emotions from them. Some said they would like to know and others said NO!

Not many days go by that I don't think about them. When I do ordinary things, to me they're EXTRAORDINARY!

I would love to hear some feedback from you, which I know your brain and HEART have something to say to me! Am I right about that?

Jim, you know that I have been part of the transplant world for 25 years and I have seen the changes. Communication is the number one change I've seen with the amount of support and information for patients and their families. Twenty-five years ago, we had nothing on the scale that it is today. I remember oh so well, when Dr. Bannett approached me with the idea about KIDNEY1 (a new concept then, known as an OPO now)that he was putting into place and he asked me if I would be interested in helping out with this unique program. I'm quite certain that I was the first patient to go out to hospitals, seminars, conventions or anyone who would listen to our quest about transplantation! Our message was simple: transplants saves lives! Of course, the knowledge that we have now is much better than 25 years ago. Thanks to dedicated researchers, and others, our quality of life has improved enormously! I'm very proud to have been part of the onset of KIDNEY1 and I'm still alive to talk about the greatness of The Gift Of Life!

Well Jim, we do have something in common - once we start talking about transplantation, we can't STOP!
God Bless You. ~Joanne~
(Note: in this next beautiful sharing, the wife of a liver recipient shares her thoughts as well as the letter she wrote their donor on behalf of her entire family, serving as yet another example for your own letter writing.)

Subj: Letter to Donor Family  
Date: 8/16/99 12:47:00 PM Eastern Daylight Time  
From: wife of a liver transplant recipient  
To: GleasonJim

Jim,
In the 20 months I have silently gained insight, understanding, and respect for the transplant community, and you personally, from all your postings. My husband received a liver transplant in 12/97, and you have been an inspiration on numerous occasions. He had only been on the list for three months, so the whole idea of a transplant was relatively new to us when he "crashed" with a portal vein occlusion. He got so sick he had to be life-flighted to a transplant center 50 miles from us, and remained in the hospital until surgery.

I would like to help you with your brochure regarding recipient/donor correspondence. It was over a year after the transplant that I finally was able to author a letter to our donor family. My husband worked for more that 20 years in emergency medicine, and in those years he had the experience too many times of hearing a mother's scream when she has been told that her child was dead - and it was that memory that kept my husband from being able to write - you see, we had been told that the donor was a 19 year old, and the surgery was exactly one week before Christmas. So I finally wrote the letter from our entire family.

We have received a letter in response, from the donor's mother. In it, she consoles us, letting us know that her daughter (whose name was Charity!!!) made the decision on her 18th birthday to become an Organ Donor, and told her family. So when the time came, her mother felt it was a decision that had already been made. My husband cannot read it without crying, it is a subject that is so incredibly personal.

I am attaching my original letter, please I hope I can figure out how to do this. If this letter comes through to you without an attachment, let me know and I'll try it again.

Please keep doing what you're doing - and include the pictures of that beautiful granddaughter!

December 30th 1998

==============================================================================
Dear Donor Family,

Although it has been just over a year since the transplant, this letter has been written hundreds of times, always in my mind. How do I start it? What can I possibly say to ease the grief this family must be feeling? The words are not easy to find, “thank you” seems so inadequate to express our appreciation. This letter comes from a Recipient Family, as we all received the most precious Gift of Life.

My husband underwent his liver transplant on December 18th 1997; a new chance at living, and you made it possible. John had been hospitalized for a month, his liver failing rapidly. It was difficult to watch him deteriorate; the most simple tasks a burden, and some days having trouble remembering his own name. At 41, a paramedic and father of six, he had always been the provider of care and strength of our family. But the hepatitis that attacked his liver, contracted from a patient he had saved, changed everything.

The morning of surgery, I stood in a hospital waiting room and watched as a helicopter landed on the rooftop of a nearby building. That helicopter was delivering more than a liver; it was bringing a future, the beginning of the rest of our lives. Not a day goes by that we don’t identify how easily we could have lost our tomorrows together.

This last year has given us an opportunity to watch as a child graduates from high school, another moving out on her own for the first time, the ability to hold a brand new niece, or take pictures on prom night.

We revel in the simple pleasures of walking hand in hand, or watching a bird at a feeder.

We have become out spoken advocates for Organ Donation, trying somehow to repay the debt that we feel. John has reached out to other transplant candidates and recipients, to counsel or just share an experience as only he can. Maybe in some way we can make a difference in someone else’s life.

The simple words “thank you” cannot begin to express the depth of gratitude, and emotion that we feel. We hope this letter
has helped your family at a very difficult time, and conveyed how special you are to us. You will forever be in our hearts.

Sincerely,

==============================================================================

(Note: now we hear from a donor mom and can see why sometimes you as a recipient may not receive an immediate response to your letter of thanks, even if it is delivered to the donor family. I have heard this same story many times - that a donor family member may not be ready to respond to such a letter in those early months/years. You have no way of knowing this at the time, of course. That’s where support from the OPO and transplant center process helps sometimes. Write that letter, softly and with compassion, and trust that someone needs to hear from you, either now or later. Following her original note, follow the correspondence that developed between us and the beautiful humor shared as she recounts memories of that daughter who was the actual donor. The sad truth is that donors are often young people and the hurt the family feels can be softened by the knowledge that their loved one’s organ donation has given life to others as confirmed by your letters to the donor family. Yes, you can do something to help them: write that letter!)

Fate Has Made Us Family
...A Letter From a Donor Mom

Dear Recipient,

Almost five years ago, our lives collided and we became part of each other forever. This is truly a unique relationship since we cannot know each other. Nevertheless this is a real relationship we have. Fate has made us family. I have as much interest in your well being as your own mother, though I do not even know your name. It is so difficult for me to know what to say to you or how to say it, but I have a need to say something.

In the early days I received a lovely letter from you expressing your sympathy and thanks. I did not answer it. It was very early in my grief journey. I could not yet speak to your wishes. I could barely speak at all. Please understand that, though I did not acknowledge your words, I do still cherish them.

I have talked with many other donor families who share my quandary and many recipients who say the same. We just don't know what to say. In the years since that day that brought us together I have done much healing. I hope you have done the same. I have built a new life, different... but fulfilling, bittersweet... without my beloved child, but not without its new joys and rewards.)
It must be very difficult for you to know whether to contact me and what to say since the day that gave you new life brought me the greatest pain. But it is a day that we will each mark every year, you in joy and I in sorrow. I thought perhaps it was time to share with you what I truly need from this eternal relationship of ours, especially on that particular day.

Every year on our anniversary, I need to know:
You are alive and well.
You do not forget.
You are taking very good care of this precious piece, as I did of the whole.
I do not need flowery words of condolence nor a detailed report of your progress. If you simply take the time to buy a card and send it I will know all I need to know. That I am not alone in this remembering, that this gift was as well received as it was given.

Live long and prosper,
Your Donor's Mom

In following up with this donor mom, she graciously replied to my request to share her note above as a way of helping others deal with this communications issue. She put her replies between the comments made in my original note to her as follows:

Jim wrote: I'm glad you are still here interacting with the community/family we have found ourselves with.

She responded: I'm here, Jim, looking for some clue that those recipients are still out there, alive and well. I have been unable to get any information about them since very early on. I would so much love to hear from them now, now that I am finally ready.

I very much meant what I said in the letter. It has been almost 12 years now and I'm fine... most of the time. The anniversary of her death is still very difficult for me, probably made worse by the fact that it was St Patrick's Day so even the media reminds me what day it is. It would truly make my day to just once get an anonymous "Thinking of You" card on that day. It has never happened though. It has become the loneliest day of my year. I go out of my way to make busy plans in hopes of avoiding the reality.

Jim wrote: We all need to touch someone like your lovely daughter, Johanna, to keep our own life saving transplant gifts in perspective.

As a heart recipient from back in '94, I offer you my own thanks for honoring your daughter's wishes and for raising such a fine lady who made such a decision herself thanks to your upbringing.

May I use your beautiful note in an upcoming chapter of my book, A GIFT FROM THE HEART?
She wrote: By all means, Jim, with my blessing! Johanna dreamed of being famous one day. I know she would be delighted!

Jim wrote: There is a chapter there on Donor Communications and I try to educate transplant recipients on how to write and how important it is to reach out to their donor family to offer their thanks.

She wrote: I think the most important key here is "not too soon." Grief is an ongoing and lengthy process. It takes a very long time before we are ready to talk about it... or even think about it.

AND... the donor process is pretty traumatizing too. You cannot imagine what a difficult choice this is to make at the time you need to be making it. The only way I could bring myself to it was to continuously remind myself that I promised Jo and I needed to keep my promise. I can't tell you how many times I almost changed my mind. I have never been sorry, though.

Jim wrote: Your note gives them the insight they need to move past their fears of hurting the donor family with their so inadequate words in a way I cannot even hope to explain myself. If you agree, do you want me to leave it without your name on it, sort of speaking on behalf of all donor families with what you say, or would you like me to add a link to your beautiful web site for them to relate it to Johanna?

She wrote: Let Johanna speak please?

I would guess that most donor families do feel as I do... but I would not put words in their mouths.

You might also investigate our links to GriefNet. There's real support there for those who need it. I have talked with hundreds of other Moms like me through them. One of them has since become my best friend in all the world.

Through GN I have known a few parents who've lost children who simply closed the door on it and never spoke of it again. Everyone grieves differently.

Jim wrote: I look forward to helping you reach out in this way to an even wider audience with your message.

She wrote: Amen and amen... you could give Johanna no greater gift than an audience! I can almost hear her giggling! I wish you could have heard her giggle! It was so infectious!

Johanna's mother wrote:

Hi everyone,

I haven't posted in a long time. I am a donor Mom since 1993. Would you care to meet my Johanna, who MADE me promise to donate her organs when she was only 13 years old? http://www.geocities.com/jo31793/johanna.html

(Jim's note: Johanna was 14 when she died. At this web site you will meet Johanna and be prepared, the messages there are written as if Johanna was the one speaking them to you...)

For you newer recipients, I wrote a letter to you and those like you a few years back. It's been posted at
Transweb for 7 years now but it is just as relevant today as then...

http://www.transweb.org/people/donors/messages/dear_recip2.html
(Jim’s note: this link is to the same letter that is shown earlier leading into this dialogue…)

(Jim’s note: and our correspondence took another smiling turn when she wrote back again… and please do not take her reference to “youngster” and her thoughts on that negatively in any way. It’s just another interesting way to think about all this and reverses her earlier concerns about where her donation went. Obviously, only being still a youngster at heart myself, you can read that my heart understood her intentions (smile!).)

From: Jo’s mom (again)
To: <GleasonJim@aol.com>
Subject: Re: Been reading your stuff...
Date: Tue, 22 Feb 2005 09:08:07 -0600

I'm finding a new blessing in your writing...

There are so many issues about organ donation that we donors don't realize until after the fact because we are not intellectually adept enough when our child is lying dying to formulate the questions. I truly think there needs to be a way to address these issues in the form of raising public awareness before the fact. (There are a lot. I'll be happy to share with you later if you're interested.) The one you've helped me resolve is what I want to tell you about.

One of the things that I just naturally assumed was that Jo's organs would automatically go to kids. (I know the science now, no need to fill me in.) When Jo's heart was placed in a 60 year old grand father in Ormond Beach I was disappointed, thinking that her 14 year old heart had so many more miles on it... and wondering how long this Grandpa could possibly survive with it. Reading your words I realize that it is entirely possible that he might live almost as long as a younger person could. He may well be 72 now... "with miles to go before he sleeps."

Reading your joy in living your life reaffirms this. I'm realizing for the first time that this guy in Ormond Beach is probably infinitely more capable of knowing the greatness of our sacrifice than any youngster could!

For the first time since it happened... I am glad this robust heart resides in the chest of a man who is mature enough to really enjoy it... and really put it to good use!

Thanks again! Bet you never thought that one of us would ever be thanking one of you! *giggles*

- Jo’s mom

Jim wrote back to her again:
I can't adequately express in words what your sharing means to me. Yes, you have me right in your description and in offering my heart to others such as yourself it is amazing to see how that heart continues to give even beyond my own life. Thank you for sharing back as you did. You make my own heart "giggle" and I can just feel Jo (your "sunshine") smiling down on us both at such goings on. There is no doubt in my mind that our loved ones stay with us and somehow make things like this happen all the time. Jo certainly orchestrated this between us
as her way of giving some sunshine in your day (and mine too!).

Thank you for your sharing. And yes, we "grandpas" certainly do appreciate such gifts much more than our younger members......

Jim Gleason

The following full length story was shared by another close friend of many years. She has since married and is today the mother of two very healthy girls, proving just how much difference a donation decision can have on another’s life.

She writes:
While attending a Christmas Party in 1994 at the Delaware Valley Transplant Program, now known as the Gift of Life Donor Program, I met Beth Sturgill Hahn, who was a transplant coordinator. She introduced herself to me and told me that she recognized my name because she was the coordinator who went to York hospital two and a half years earlier to talk to the Shriver family about organ donation. It was interesting to hear her talk of what was involved that weekend in handling the Shriver family’s request for Doug’s organs to be donated and I appreciated her being so friendly and open with me.

Beth assured me that, although I had not heard back from Doug’s family, my thank you letters had been sent to them. The letters did not include my name and address as requested by the transplant program. It is difficult to write letters to your donor family for many reasons. I had a hard time writing to strangers who lost someone they loved and I was saying thanks because a tragedy in their family. It was something I had to do and my letters were short but whether they knew it or not, from someone who was more grateful than she could express.

In the summer of 1995 I received my first letter from Doug’s sister, Cheryl. She told me how we had many things in common. We were both born in June 1961, were the oldest of four children and had two brothers and a sister. Cheryl had two daughters though and I had no children at that time. Now, years later I also have two daughters.

My niece, Heather was like a daughter to me and Cheryl picked up on this in my letters and told me that she had a daughter Heather, who was the same age as my niece. Both Heather’s eventually met each other and became pen pals as Cheryl and I had.
Cheryl thanked me for my letters and the letters my mother wrote to her family. She also wanted to meet my mother and I someday. Through the Delaware Valley Transplant Program, we exchanged phone numbers and set up a meeting. My mother and I traveled about three hours to Gettysburg and visited with Cheryl, her husband Mike and their two daughters, Heather and Ashton.

I learned on that first trip that no other members of Doug’s family would like to meet me. This was not important to me. What I found much more important was that they know how incredibly thankful I am for their decision to donate Doug’s kidney and pancreas.

While visiting, Cheryl shared two articles about Doug being an organ donor written by Joe Martin of The Evening Sun newspaper in Hanover, PA. One of the articles told of the other recipients of Doug’s organs.

**As written by Joe Martin:**

Doug's liver was transplanted to a woman in Pittsburgh who had worked as a bookkeeper. At the time of the transplant she was very ill in the intensive care unit and not expected to live more than a few days without a transplant.

It is not known what caused her liver failure. However, although she remains very ill the "new" liver is functioning very well and the surgeons are optimistic there will be a full recovery.

Although life has stopped in one, it can still go on in another.

One of Doug's kidneys was transplanted to a gentleman from Philadelphia. He is married, and before he became disabled from kidney failure he worked as a realtor. He had been on dialysis for three years and waiting for a transplant for two years.

Now, thanks to Doug's gift, he no longer requires dialysis and his "new" kidney is functioning normally. He hopes to be able to return to work shortly.

What greater gift could one possibly receive? I know of none!

Beth Sturgill, the transplant coordinator for the Delaware Valley Program, who handled the Shriver case, also included in her report to Dorothy and Paul, more detailed information on the other three lucky recipients.
The heart transplant patient is a 46 year old single gentleman who worked as a machinist in Delaware. He had been suffering severe artery disease and had been waiting nearly a year for a transplant.

As we said, he is doing very well and in all probability will be home by the time this is published. I'll bet Doug is smiling about now!

The other kidney and pancreas were transplanted to a 30 year old woman. That we knew. What we didn't know before is that she is an accountant who had diabetes and been waiting for a transplant for several months.

Since the transplant she has done very well and no longer needs insulin; her "new" kidney function is also normal. She, too, is home by now. Marvelous.

Finally the cornea was transplanted to a 31 year old patient who lost vision due to an infection of the cornea. The transplant went very well and the patient is regaining the "precious gift of sight." Nothing more need be said. The Shriver story, in my book, is the perfect example of "love and help."

Faith now continues:
I was impressed with Joe’s inspiring words and wanted to let him know how thankful I was for his articles encouraging organ donation and how great this recipient was doing. But I was hesitant because I did not want to do anything that would offend anyone in Doug’s family and I knew there was a possibility that Joe Martin could publish what I wrote. I contacted Cheryl and asked her opinion and she gave me a very encouraging go ahead.

Joe did publish my letter in the Evening Sun shortly after receiving it. Here is a copy of the article that appeared in December 1996.
The Gift of Giving was never so important
The Evening Sun
Saturday December 21, 1996

Four days from now will be Christmas. A time when Christianity celebrates the birth of Jesus Christ. It's also a time for giving, and what could be more appropriate than giving a part of one's body that another may live?

Charles Dickens' Christmas Carol teaches us that giving is a blessed way to celebrate Christmas. Well, what you are about to read, I think, is the true essence of the spirit of Christmas.

Last month I received a letter from Faith Taylor of Horsham, PA Just north of Philly. I've held it until today because I think it makes the perfect Christmas story. I quote the letter in its entirety:

"Dear Mr. Martin:

Thank you for writing the two articles in 1992 regarding Paul and Dorothy Shriver's decision to allow their son's vital organs to be transplanted after he died following an automobile accident. I was given the articles just recently and I cherish them.

I am the recipient of Doug's kidney and pancreas. My life has been blessed since that tragic day for Doug's family.

When I was in my twenties, I already showed signs of complications from diabetes. I had been told that I could be blind by age 40 and on dialysis by age 30. Although I tried to stop the complications from this disease by eating well, exercising and following doctors' orders, they happened.

I was 27 when I started with the laser surgeries on my eyes to prevent blindness, and around that time I was told it would be about two years until I needed dialysis. Everything was going as predicted, blindness and dialysis.

At the same time, my beloved husband of seven years was dying of leukemia. We had been married for three years when he was diagnosed with leukemia. Although we tried everything possible to save his life, he died in 1988 at age 27. My heart was truly broken and I thought I would never recover.

In January of 1992, I toured the dialysis unit of a local hospital with my doctor to prepare for the day I would begin coming three times a week. I did not know how I would continue to work full time and keep up my routine but I would figure that out when the time came.

I also thought about my eyesight. How would I live without my sight? I enjoy all of God's beautiful creations. I love to draw and paint. So much
would be missing without my sight. The thoughts were almost too much to bear. I went on, trying not to dwell on my health problems.

That very night I heard the most amazing thing from my doctor for the first time. Have you ever considered having a kidney and pancreas transplant, he asked. After some discussion, I decided I was going to visit a hospital in Philadelphia and see what this was all about.

In February 1992, I started seeing every type of doctor that exists to be evaluated for the surgery. In March 1992, I was placed on the waiting list and carried a beeper whenever I left my home. I tried not to think too much about the fact that someone had to die for my transplant to take place.

On July 6, 1992, I was called to the hospital and prepped for surgery. A short time earlier, the family of Douglas Shriver made the decision to donate the organs of their 27 year old son and brother. The morning of July 7, 1992, Doug's pancreas and one of his kidneys immediately took over where my body was failing.

His pancreas has produced the perfect amount of insulin and kept me from daily insulin shots. His kidney has purified my blood and kept me off dialysis now for four years and four months. I have had no further complications from diabetes since the date of my transplant. I have 20/20 vision (with glasses for hereditary nearsightedness). My ophthalmologist told me last week that because my eyes have been so stable for the past four years, she doubts I will have any more problems.

My life has been so blessed because of the miracle of organ donation. As you can imagine, I never dreamed I would be so healthy at the age of 35. I work full time in an insurance company and hope to become a transplant coordinator for this same Company.

To reach this goal, I am taking college courses in nursing part time. My new cause, organ donation, has kept me very busy also. I speak to many groups about life after transplantation. I also organize an all day conference attended by about 400 recipients bi-annually that keeps us current on transplant issues such as medications, insurance and keeping healthy through exercise and diet. We also have a session on how to write to say thank-you to your donor family.

In August of this year, about 1200 recipients of life saving organs gathered in Salt Lake City, Utah for the 1996 U.S. Transplant Games. It was one of the most beautiful experiences of my life. The teams from all over the U.S. were proving that organ donation works.

There were very healthy athletes competing and others who just wanted to be there and meet fellow transplant recipients and donor families. We
were blessed by the presence of 60-75 donor families who were honored with a Gift of Life medal.

Additionally, there was a quilt, called "Patches of Love." Each patch was given by a donor family to honor their loved one. Some had a picture of the donor or a poem about the donor. I trained for many months before the games and won a bronze medal in the 1K bike race. It is so great to be healthy.

I am sorry this is so long but I wanted you to know how much I appreciate what the Shriver family has done. My thoughts and prayers are continually with Doug and his family.

Thank you for your interest and care.

Forever grateful,
- Faith Taylor"

After reading Faith's letter, I looked up those two 1992 columns. Doug had lived with his Mom and Dad on a farm in Adams County a couple of miles outside of Gettysburg when he died in an automobile accident. Besides Faith's new gift of life, a gentleman in Philadelphia received Doug's other kidney, and he too was off dialysis.

Doug's heart was beating in the chest of a then-46 year old machinist in Delaware. And a cornea transplant brought sight to a 31 year old patient who had been sightless. I can't think of any gift greater than those.

We have a bumper sticker that pretty well sums up Faith's and our opinion of the organ donor program. It reads: "Don't take your organs to Heaven. Heaven knows we need them here."

Merry Christmas everyone, and remember to sign up to be an organ donor. And don't forget "after the verb 'To Love', 'To Help' is the most beautiful verb in the world. Merry Christmas. Thank you, Faith.

Pax vobiscum.

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Faith continues:

Joe Martin spoke with Dorothy and Paul Shriver about publishing the article and I was very happy to learn that they wished to meet me after reading my letter. On Sunday, January 12, 1997, my mother and I had the pleasure of meeting with Doug’s parents, his daughter Jodi, his sister Karen Shriver Tawney and her daughter Carrie. We saw Cheryl, Mike, Heather and Ashton Slaybaugh again and met Joe Martin and his wife Evelyn. We all met at the home of Dorothy and Paul that sits on a beautiful 96 acre farm in Gettysburg. A photographer from the Evening Sun was there and I was happy to have photos of this very special time. Mr. Martin published another story about us meeting along with a photo.

It was a special and unique experience to see where my donor lived and the people closest to him. My first view when we arrived was that of a beautiful farm with fields that went on as far as your eyes could see. I thought of Doug working with his father in these fields and how much he was missed.

We all sat together and enjoyed watching family videos that included Doug working with his father on their farm and helping Jodi find Easter eggs on the family Easter egg hunt. Because they had video, I had the unique experience of seeing him while he was alive. I remember thinking that the kidney and pancreas inside of me was on that video too.

We also liked hearing about the many practical jokes he loved to pull on his mother. I felt proud to know my donor was such a handsome, strong, and witty young man who cared about others and was such a great help to his father.

The Shriver family is warm, loving and close and I feel so blessed to have been able to meet them. To top it off, Doug’s sister, Karen, invited my family to their family picnic at her home that summer with the words, "you are now a part of our family."

My mother, niece Heather and I attended that family reunion and met many other very loving members of Doug’s family. My gratitude to this family is enormous and their generosity and example has touched the lives of countless others.
And now from a more recent posting reply:

April 2005

Dear Jim,

I re-visited Transweb.org as you suggested and this time it worked when I tried a search for Gleason. Read a little of your writings with interest. I've been trying to help a dear friend in Colorado whose husband needs a liver transplant. Keep trying to come up with ideas of what to throw into a box to have handy for that ride to the transplant hospital many miles away. You wrote about music and a CD player, which sparked my memory. You are absolutely right. I think I missed music more than Frank. I bought him a small clock radio that plays CD's, but it didn't have earphones and even though the volume was turned very low, sometimes a nurse would say we had to turn it off. But it did help with the boredom.

Yes, I agree that every organ transplant recipient should write his/her letter of thanks to the donor. After Frank's liver transplant July 31, 2003, and once we settled in back at home, I went to a number of Stationary stores looking for just the right or most perfect Thank You cards I could find. And then we both wrote our Thank You letters to the donors' family. It wasn't just Frank the recipient who was thankful. I needed to write my own letter. Those letters where the hardest letters to write. It took us a long time to write them. We knew our donor was male, his age, and the life saving liver came from the Los Vegas area. Frank had the disadvantage of still having some confusion due to medications. I think Frank forgot he was writing to the family of his donor; the people who had lost a loved one and were grieving. The person who would read the letter would maybe be the donor's wife, or mother, or sister, or daughter or son....we didn't know. Frank's letter at first read like he was writing to the donor himself. So, I had to gently point this out to him, and to be careful what he wrote as it would probably be the man's wife who would get the letter. I suggested he put himself in her shoes. Mere words don't really express all the heartfelt feelings and profound gratitude you feel. And simply saying Thank You isn't nearly enough. And of course the hospital, who would forward our letters, put restrictions on what you could include. You couldn't include anything that identified yourself like a last name or where you lived, or reference even to religion, etc. We felt and still feel we owed so much to this family. My husband's very life. A part of me hoped that we might hear back from our donor family...but we respect their privacy and their grief.

Warmly,
Frank's wife, Linda

Later, Linda wrote again (allowing use of her name) to share more thoughts and another example of a thank you letter as she wrote it to their donor family:
Hello to Everyone,

This is especially for Jim Gleason, but I thought maybe I would share it with everyone.

Jim all day I’ve been thinking about your comments and about your book...and besides sharing with you the paragraph I wrote you about agreeing that writing your donor family is so important... That for me as a spouse and caregiver of a liver transplant recipient, it was very important for me to also write my letter to the family of the donor who saved my husband's life, with that precious GIFT of LIFE. And so I share with you now:

My Letter of Love and Appreciation to our Donor and his family –

Please accept our Deepest Sympathies for your loss. And our Greatest Appreciation for your Precious Gift of Life. In your time of grief you did a Wonderful thing, for which we will be Forever Abundantly Grateful. May time lessen and soften your grief.

You have given to someone you don’t even know, a precious second chance at Life. We don’t know your names to extend our personal heartfelt THANK YOU from the depths of our hearts, but You are in our daily thoughts and prayers, as we Thank God for Our Donor and his Family. Such Special People; who will be forever such a significant part of our lives and our future. Your Most Thoughtful Loving Kindness saved another human being’s life. YOU are our Champion and Hero. There could be no greater or more precious gift in all the Universe. And we are Blessed.

Maybe you would like to know a little about your Recipient: My Beloved husband’s name is Frank. About forty years ago, and through no fault of his own, he contracted Hepatitis C from a doctor recommended Gamma-Globulin injection when one of his fellow workers reported having Hepatitis A. For the protection of his family, Frank took the injection as he had a pregnant wife at home carrying his third child. As the years passed he became ill, but it wasn’t until Feb. 1993 that he learned he had Hepatitis C. And although he didn’t drink and took excellent care of himself and his liver, the Hep. C virus took its toll resulting in “End Stage Liver Disease”. Frank had been very ill and was in both our local hospitals, for multiple blood transfusions etc. It’s not an easy thing to watch someone you love hemorrhage and vomit two liters of blood. Although he was gravely ill with “End Stage Liver Disease” which brings with it confusion due to increased ammonia levels in the blood, Frank told his doctor he wanted to go home, and the doctor couldn’t/didn’t refuse discharging him. That suddenly left me with a seriously ill and confused husband at home. He wondered the house all night long, with diarrhea and vomiting, totally confused and as if trying to get away from himself. While trying to take care of Frank, I was also busy during the night packing the car for our unknown future. My one goal was to keep my husband alive. Our two local hospitals couldn’t help him. I knew if we stayed home he would die. Next morning I hired a disabled transport van and at noon we started the three-hour trip into the Los Angeles area, arriving at UCLA Medical Center Emergency Room at 3:00 in the afternoon. At 3:00 in the morning, June 6, they finally found a bed for him on the sixth floor and Frank was admitted and started the evaluation process for a possible Liver Transplant. I knew in the back of my head that if we left UCLA, Frank would die. For the longest two months of my life, I was at his bedside every day, all day, and into the night, sleeping in the car in order to be as close as possible. As I watched my husband heading faster and faster towards the last days of his life… I hung onto the thought that there is something good in everything. Even when his lab tests showed increasing liver and renal failure, I had to tell myself this needed to happen in order for him to have a chance at getting a liver transplant...our only hope.

The Miracle Call came to me about 10.30 p.m. on July 30th. I was told they had a liver for my husband, and Frank’s Transplant surgery would begin at 5:00 a.m. After a moment of disbelief, confirmation and a Big THANK YOU, I asked and was told that our Donor was a 39 year old male. I then rushed to tell Frank…. We cried. We Thanked God, and our Donor. After the pre-Op tests were done...
including drawing 15 vials of blood, Frank went to sleep. I went to the large window down the hall, Thanked God and our Donor again, and waited and watched as our Helicopter arrived at 2:20 a.m., bringing our most Precious Gift from Nevada. The life saving surgery took 7 hours. 103 days in three hospitals; 78 days at UCLA - And Thanks to You, my husband is Alive, Profoundly Grateful, and Blessed. We have seven children and nine grandchildren, who Thanks to you have their Father and Grandfather. By your life giving donation many lives have been positively affected. And we all Bless the Memory of Our Donor.
With Much Love,

Linda

To her sharing above, I responded to both her and the group members of this mailing list:

Date: Tue, 26 Apr 2005 09:29:26 -0400
From: GleasonJim@aol.com
Subject: Re: Digest Number 27

Linda, I sit here with tears in my eyes as I finished reading your beautiful letter of gratitude to your husband's donor family. I will gladly accept your note to include in that new chapter of my book (A Gift from the Heart) on donor family communications. Thank you for that sharing. I pray that it motivates others to overcome their fear of writing that ever so important letter to their own donors. Yes, it is hard, but imagine the donor wondering why - why they never get such a letter, even a much simpler one, that just says it all in "Thank you for giving our family life!" To one who has given such a gift it makes no sense that someone wouldn't at least write that simple note. To everyone out there: If you haven't done it yet, please take Linda's example to heart and write it now. It doesn't have to be as complete or detailed as hers. Just say "Thank you!" It can mean so much....

Thank you Linda, for offering us all that example and encouragement to write.

- Jim Gleason

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Note: as this chapter was sent out for review, several new e-mails sharing experiences with Donor Communications came back. Some were just too beautiful to not include here for your additional reading pleasure. One of the unique benefits of virtual publishing is that such updates can be done anytime and the next one sent out has the new version. In that sense, this chapter (in fact this whole book...) may never be finished. I hope you enjoy the benefits of such “virtual publishing” like this....
From: a heart recipient who is also a donor mom
To: GLEASONJIM@aol.com
Sent: Tue, 03 May 2005 10:30:43 -0500
Subject: With heart

Jim,

As a new member of this forum I have read with interest your posts. I had a heart transplant July 2, 2003 at Carolinas Medical Center in Charlotte. I thought I’d send you the letter I wrote my donor family in November of that year. Due to the new HIPA regulations, all I know of my donor is that they were only 20 years old. I suspect she was female as the heart was too small for the man ahead of me on the list. I have not yet read your publication but will and am sure I'll see many unique stories.

I had become so ill I was almost taken off the list. My cardiologist helped to keep me on but I don't think I had much longer. During surgery, after my heart was in, the doctors were unable to get it to restart. The surgery drug on. As they were about to put me on a mechanical heart and look for another organ, it started. I had a very difficult recovery. But I keep improving as time goes on.

After everything everyone has done to keep me alive, I must be diligent to honor their work.
- a heart recipient/donor mom

Her letter: November 23, 2003
To my donor family,

I am a 49-year old mother of two. I am a free-lance graphic designer, my husband is a production manager. My daughter is 24, my son 18. We will be married 30 years in 2004.

I was born with congenital heart defects which caused congestive heart failure. I unfortunately passed these defects on to my son. Last year I was placed on the transplant list and I felt my condition really began to deteriorate; I didn’t think I’d live long enough for a heart. When I received the call from the transplant hospital I was relieved, but cried for your loved one. I spent a great deal of time thinking about her/him, and you, the family. No one should have to lose someone so young, I thought, but how much strength it must have taken to save the lives of others.

About 10 weeks after my transplant I was where you were. My son died of a massive heart attack while at college, due to his heart defects. We also donated what we could. I hope he was able to help someone else.

I know exactly what you have gone through. The loss is terrible, it will never go away. But you have saved my life. I know I have to do something with this life. I am taking care of myself, and this heart, as I cherish it. Because of you I was able to spend the last weeks of my son’s life alive, with him, and be here to comfort my husband and daughter after his death.

You are heroes.
Thank you.
Hi Jim,
I realize that I'm a little late, but I do want to share this experience I had with my donor family.

Here's the short version:
My donor family wrote to me, telling of a certain star in the sky they had dedicated in memory of their sixteen year old son, Christopher. They wrote that this star was for me and my friends to look at and to know that Christopher was watching over us. I was very touched by this, so in response I created a sterling silver star pendant for them. I told them, "I know that this star is not as perfect as those in the heavens, but understand that it comes from my heart and is made with love and appreciation for your greatest gift."

I call this star symbol "The Star of Life". The spiral in the center represents the donor's life which flows to become a whole new form...a star. The points of the star represent the lives touched and the lives saved by organ and tissue donation. Christopher's mom always wears her Star and I always wear one too - in honor of Christopher and of all organ donors.

Jim - I don't know if you've seen one of my Star of Life necklaces. I gave about 200 to donor families at the '98 TX Games and again at the '04 Games. My team, Northern California, uses the Star of Life as our team logo. I tell the Star story and give the Star necklaces to donor families at both of the northern California OPO's annual donor recognition ceremonies. I've made about 2,000 to date. The families love receiving something tangible and handcrafted from an appreciative recipient. I get the best thank you notes!!!

Thanks for all you do,

MBW,
a 1997 kidney & pancreas recipient
And here are some more insights into the heart of another recipient who shared these words with a transplant support group recently and offered them for inclusion in this chapter to help you:

I've been following this line of discussion attentively; it's a subject that often comes up in the transplant group that I moderate, and it's generally written about with great passion. I'm sorry that I got to replying so late in the game.

Prior to my transplant, I sat through several meetings of the brick and mortar support group and listened to the stories about writing those letters. I was always a bit of a skeptic when folks talked about how tough it was to write that first letter. After my transplant, I had a bit of a different perspective; the other stories I've heard are much the same, in that writing that letter is one of the hardest, most emotional things a transplant patient can do.

I'd had my transplant for about four months when I started to feel the need to start writing; I'd heard several times about the recommendation to wait for a year before initiating contact, and while I understood the reasons for that recommendation, I really needed to at least start putting my letter together. I started to put it together for two months; if my drafts were made out of paper rather than kilobytes, I imagine I'd have thrown out about a room full o' paper. I'd included facts, figures, and perhaps everything but a bibliography. I was frustrated to no end, because nothing was coming out right.

I was at the support group meeting one day when the subject arose; it turns out more than one person was having that problem. I didn't really chime in, and barely took notice when another guy in the group said "Just write it from your heart". It wasn't until I got home that I *really* thought about that, but the thought that came to me was "Just write it from your donor's heart". The letter that I eventually sent took me twenty minutes to write from start to finish.

I know some of the stories mentioned here, about negative experiences after having written that letter are true; I received the same cautions in my support group, and I've in fact heard similar stories from some friends of mine. In my case, though, the experience proved to be cathartic, in the writing, and an unbelievable blessing in the reply that I received. I got the reply about two months after I gave the letter to Life Center Northwest (the Organ Procurement Organization in my area, and the organization with primary responsibility for Donor - Recipient relations). I was sick with a rotten head cold that day, and I needed some encouragement...hoo boy, did I get it. I picked up the mail at around 5:15 in the afternoon, and when my girlfriend at the time got home, about fifteen minutes later, I'd read it about thirty times. She walked in, saw me sitting at the couch with tears running down my face, and before she had a chance to ask me what the matter was, I simply said "His name was Tom". She understood immediately. Tom's wife, Kristin, had written; she told me, among other things, than my letter
had validated the hardest decision she'd ever had to make on what was the hardest day of her life, and that her decision was the only good thing to come out of that day. She said that, much like happened when I read "her" letter, that when she saw mine, she'd sobbed for hours, from grief for Tom, certainly, but also with a sense of fulfillment and completion. I wrote her again some time later; in her reply to my second letter, she said that she and her kids were having a rough time, and asked for some time. I've given her that; I hope that we can one day get in touch again, but in the meantime, she knows of my gratitude and my love, and she knows the name of the person in whom Tom's heart now beats. I'm really not sure how I could ask for much more than that.

Writing that letter was agonizing; it brought up feelings in me that I'm not sure I want to feel again in my life, but the person to whom I wrote it "saved" that very life. I felt then, and feel now, that I owed her that thanks; Tom, you see, is a very special hero to me for obvious reasons, but the "real" hero, in my eyes, is Kristen; "she" had to make the final decision, and "she" has to live with the memory of making that decision while knowing that her husband's chest was still rising and falling with his breath. I can't even conceive of the courage and the love that it took to make that decision.

I've thought long and hard about what I'm writing tonight, and what I'm posting with this email. I'm including a link to the letter I wrote. Part of the reason is probably for you, Cheryl. I'd like for you to have received a reply to the letters that you wrote, and though I think you should have, I also know how terribly difficult it is; I know some very good people who are years removed from their transplants...people who'd give anything to write that letter to say thanks, and simply can't bring themselves to do it. They know, though...they know that without people like you, like Lori...and like Kristen, that they wouldn't be here. They're more grateful for that than you may ever know, but some of them are just so grateful that...they just can't say it. This letter, then, is for the donors and their families; it's also for the folks that may be having trouble saying thanks; it's a hard thing to do, and as has been mentioned several times in this group, the reply you get, if any, isn't always gonna be what you want to hear. In my opinion, though...and I can't speak for anyone else...it's worth it, just to give those thanks.

http://home.comcast.net/~unclfester/letter.html

The thing is, Cheryl, you *are* someone's hero, whether they've told you that or not. You're certainly a hero to me, as is Lori, and as is Kristin. Thank you...to all of you...for what you had the love and the courage to do.

Grace and peace,

Steve Cardiac tx # 340, UWMC
Puyallup, WA
unclfester@gmail.com
And now, that last part . . .

. . . that I promised you way back in the introduction to this chapter. What follows is the full story of a donor family’s experience in reaching out to one of their recipients and the correspondence that resulted, including the meeting between them that finally took place. In this series of saved letters and e-mails, I had the opportunity to interview the donor family and capture some of the feelings that preceded the letters, some of the expectations that led up to such correspondence and the face-to-face meeting, followed by what has happened since that meeting up until the time this section is written. While this is one family’s experience, it allows us a rare look into the total experience over the course of seven years. Again I remind you as you read this beautiful sharing, what you see here is neither the right nor wrong way to do it. Just take from their experience what you will for your own inspiration to in turn do what you feel is right in your circumstances.

First, an overview:

Pam writes:
Each day we awake to continue our journey each with a different purpose, not always certain what that may be. My journey was drastically changed on May 21, 1997. On this beautiful spring afternoon my son, Christopher was stricken by a speeding motorist while bike riding, the following morning pronounced brain dead. He was an avid re-cycler and loved life, giving to others at every opportunity, thus making the decision to donate without question.

A year passed, still with a very heavy heart I attended a donor recognition ceremony having no idea my journey would change once again. I met Anthony, a heart recipient and his wife Donna along with Jim and Michele the parents of a double-lung recipient, I was in awe and inspired by their stories and seeing first hand how their gift allowed them to lead normal lives, in fact better lives. A heartfelt thank you to them for they may not know it but they saved my life that night.

I was now determined to communicate with Christopher’s recipients, writing letters to them, letting them know something about the loving child who had given them a second chance at life and hopefully they would tell me something about themselves.

Three years after Christopher’s death I attended the U. S. Transplant games a wonderful experience, yet there was still something missing, communication from his recipients, little did I know a letter from his liver recipient was awaiting my return home. I savored every word, grateful to finally hear, rejoicing in his health, yet with tear filled eyes at the memory of my son. For the next few months we communicated electronically, I getting to know about him, and he getting to know more about Christopher. We decided to meet.

We chose to meet at Sunset Beach, Cape May, NJ a place Christopher and I visited annually. It was a very rainy Sunday morning, driving several hours to meet Ken my mind was whirling. Just short of the destination the rain stopped and the sun shone brightly, as I drove through the very crowded and full
parking lot my heart raced, just ahead an empty space to park, a coincidence, I think not. I took a deep breath, stepped from my car, heart pounding and pulse racing. I looked up to find Ken walking toward me, as we spoke each others name he handed me a dozen roses, and we found ourselves hugging one another with a wonderful bond as bittersweet tears of joy and sadness streamed my cheeks.

We spent the day together, watching the butterflies as they migrated to Mexico, watching the waves of the ocean gently slapping the sand, and talking about he and Christopher. As the day ended I met his parents, his grandmother, and his dog. We walked his beautiful gardens as he tells me he would never have dreamed of gardening prior to transplant. His gardens have become his hobby, more like his passion, Christopher loved flowers and trees. As we parted with one last hug, not just from him but from my son as well, I was overcome with tears once more.

I will always miss my son, his smile, his humor, his love for life, but now my heart and spirit are renewed. Please consider writing that letter, whether as a donor family to your recipients or as a recipient to your donor family, you may save someone’s spirit, changing their journey as was mine.

Sincerely,
Pam, Christopher’s mom,
“...a donor mom”

Pam reached out to her son’s recipients with several letters over those first years after his death, hoping to hear anything in return. One of the recipients (both kidneys and Christopher’s liver were able to be successfully transplanted) was a cousin. During the donation process Pam suddenly recalled that her cousin was on the waiting list for a kidney, depending on dialysis for his life at the time. While it had to be an “exact match” for such a “directed donation” to occur, with odds against such a condition, as it turned out they were exact matches and that kidney did go to Pam’s cousin. Needless to say, they continue to stay in contact over the years as family visits that bring them together. It was the other two recipients that she so wanted to hear about. All she knew about them was what the OPO had written to her about two weeks after her son’s donation. I doubt any recipient has ever seen such a letter, but Pam shared hers for you to see and understand where she was at that time in knowing anything at all about her son’s recipients.
June 3, 1997

Pam Doran,
120 Elm Street L-8
Edgewater Park, N.J. 08010

Dear Mrs. Doran,

Please accept my sincere condolences to you, on the sudden loss of your son, Christopher. Your strength and courage in thinking of others during this painful time is a tribute to you and to Christopher’s memory. It is my hope that knowing the results of your generous gift will bring some sense of comfort to you and family.

Christopher’s liver was transplanted into a 39 year old single gentleman from southern N.J. He suffered from severe liver disease. He was placed on the transplant list in February of 1997. I was told that he had immediate function and is doing well.

Christopher’s right kidney was transplanted into a 35 year old man from Pennsylvania. He is married and works as a facility manager for mentally retarded children. He has had two previous transplants which failed. He has been on dialysis since 1981, we have been told that this kidney is functioning well.

As you know Christopher’s left kidney was transplanted into Mr. McDaniels. I was happy to hear that he is doing so well not only because of his relationship to your family, but because a very special part of Christopher lives on in him.

I would again like to express my sympathy and gratitude on behalf of these recipients and their families. I know that words can’t eliminate the pain that you and your family must feel, but I hope that in the months ahead you will gain comfort in knowing that you have given these precious gifts. My thoughts are with you.

Sincerely,
For three years she knew only that much. Many donor families don’t even get told that much. Would you be curious about the recipients, if not initially, at least over the years? Most donors I have spoken with do wonder. Here is her initial letter sent via the OPO in the region that serves the hospital where her son was airlifted from the accident scene.

Subject: Donor letter
Date: 8/16/99 7:53:14 PM Eastern Daylight Time
From: PCOLVELL@email.msn.com (PAMMYC)
To: GleasonJim@aol.com

Jim,
I have a copy of letter I sent to Christopher's organ recipients, I am hoping that this attachment works. Let me know if you think this could help with the upcoming project.
September 1, 1997

Dear Organ Recipient or Family Member:

I am writing this letter, hoping that you are well, and to share the story of my son, your donor.

My son, truly a gift from God, was born November 7, 1983. He was born two weeks late at 8lb 3 oz. bringing an enormous amount of joy to his father, myself, and his older sister. Unfortunately, at the age of two his father and I divorced, his sister lived with his dad, leaving just he and I to challenge the world, which made for an incredible bond between the two of us.

CRS was full of life and love, he was an active participant in several sports, playing left full back in soccer, catcher in baseball, and forward in basketball. He collected postage stamps, and antique marbles. He loved literature, and surprised his seventh grade teacher an English Literature major in college with his knowledge of Chaucer and his very favorite Shakespeare. His two favorite plays were Romeo and Juliet, and Midsummer’s Night Dream. He especially loved Shakespeare’s sonnets, and he was buried with his very worn copy which he carried everywhere with him.

He loved to fish, and bicycle, his brain death was caused by an accident while riding his bike and struck by a speeding motorist. He had just finished cutting his grandfather’s lawn just one of his many good deeds and was going to assist his father opening his pool for the Memorial Day holiday weekend, a day he never lived to see.

Although he was only 13 at death he was 6’1”, weighing 174 lbs., and wore a man’s size 13 shoe. He had sandy blond, wavy hair, and beautiful dimples when he smiled (which was most of the time). He was usually very pleasant and easy-going. His friends at school wrote many letters to me telling me that he would always make them smile and laugh no matter how bad they felt, or how bad their day was.

He was an environmentalist who enjoyed observing and protecting nature, his favorites were pink dogwood trees and yellow daffodils. He especially enjoyed a bright, clear, star filled evening when he could observe the constellations. I still enjoy looking at the stars on a clear night and wishing him well. His love of the environment and understanding for the need to recycle confirm my
A Transplant Patient’s Experiences with Communicating with a Donor Family

decision to donate his organs, please think about that the next time you throw away an aluminum can, a cardboard box, a newspaper, or an empty plastic container.

CRS was killed on a clear, warm, spring afternoon, a picture perfect day. So please enjoy each day and live a happy, fulfilled life. He would want it that way.

With his love and mine,

His mother.

Despite such annual mailing, no response was forthcoming. Finally, three years and several attempts later, she returned home from the 2000 US Transplant Games to find the following in her mailbox. Pam relates how she hesitated to open it, seeing it was from the OPO, but along with the cover note that follows, there was a second sealed envelope with the recipient’s letter inside. The cover note from the OPO read:

June 21, 2000
Dear Pam,
Hi! I expect you will receive this letter on returning from the transplant games, and I hope that you had a wonderful trip!

I am enclosing a letter that came today for you. It was written by the man who received his liver transplant from Christopher. As you know, I usually get the family’s permission prior to mailing this letter, but knowing you, I feel confident in sending it right away. Give me a call when you get a chance.

Hope you are well. Say hi to Kate for me. Hope you can make it on the 29th

Pam recalls how thoughtful the sealed recipient letter inside seemed in allowing her the decision whether to open that either immediately, or to delay it until she might be ready for such an emotional reading. As it turns out, she was excited to finally be receiving something about her son’s donor and decided to sit right down and open it without further delay.

After those earlier notes that Pam had sent (each signed “CRSs mother” where CRS are her son’s initials), only the last one had ever gotten to this recipient. Inside that OPO mailing, inside the second envelope, was the following letter:

March 7, 2000
Dear CRSs Mother,

Let me first start off by saying Thank You, to you and your late son CRS. Because of you and your unselﬁsh kindness I am alive today. When I ﬁrst received your letter I was taken back. Many quiet times I often wondered about the boy whose life was lost so I could go on living mine. Your letter was a great help in answering many of the questions I had. Your son sounded like a very intellgent, giving and unselﬁsh young man with a bright future ahead of him. It must have been a tragic loss for you and your family, I cannot even begin to imagine what it must have been like. I feel honored to have received my new liver from a young man with such a distinguished character.
I think it would be best for you to know a little bit about me. I am a 35 years old and from New Jersey. It is coming up on 3 years since my transplant. Up until now, thank God there have been no complications. I just recently visited the place where I received my transplant for my biannual check-up and they said everything was going well. They also remarked how incredibly well I looked. Needless to say I wasn’t doing that well before transplant. I was diagnosed with the latter stages of Cirrhosis almost 2 years prior to transplant. My Cirrhosis progressed pretty quickly. I was about 220 lbs when I was first diagnosed with it. Prior to transplant I was down around 120 lbs. My liver was already failing and I was told that there was little hope for me unless I received a transplant. Then on May 23, 1997 I received my life saving transplant. Once again thanks to you and your unselfish kindness.

When I was your son’s age we had much in common, as we still do today. I was about your son’s height and weight at 13 also. Currently I’m 6’4” and weighing 210 lbs. Like I said earlier I’m 35 and divorced with no kids. I too also love basketball, baseball and fishing. Another thing your son and I have in common is caring for others. Up until my illness, I worked in Nursing Homes as a Director in the Food Service Department. I always loved working with the elderly and disabled people. It brought great joy and satisfaction bringing joy into others lives. We also have humor in common too. Both in grammar and high school I was voted Class Clown of my graduating class. I love watching others smile and laugh especially when things are not going well for that person. I was always told that laughter was the best medicine. But the most amazing thing since my transplant is my new found joy in gardening. Through gardening, I have found a great deal of comfort. I plant flowers, vegetables and love landscaping the yard. As I write this letter, I anxiously await the Yellow Daffodils in my backyard to start blooming. They have already broke ground and should be blooming any day now. Pretty coincidental, I don’t think so. I am a spiritual person and I believe it’s your son still living through me. I know the experts say that people don’t acquire the traits and characteristics of their donors. However, I believe we do, but only through God’s grace.

In closing I would like to Thank You again for what you have done for me. But even more than that I would like to Thank You for sharing the story of your son. I hope that I have helped you somehow with this letter. I would love to hear from you again. I’m enclosing my address if you care to respond in that way. Or if you want to go through the same channels as before that is OK too. I just wanted you to know that I would love to continue corresponding with you and letting you know of my progress.

If you have access to a computer I have my own homepage. The 3rd page is dedicated to you and your son. The address is www.msnhomepages.talkcity.com/rightway/cmch-guy. (Jim’s note: this web site has since been lost due to that company going out of business)

With love, and gratitude,

(note: the recipient’s name and address were included here... while this is seldom done, in this case the OPO bereavement counselor knew Pam personally and felt comfortable in sharing that contact information with her....)

The following e-mails correspondence continued over the months ahead, and you will see that story unfolding in their reading here without further comment:
From: PAMMYC <PCOLVELL@email.msn.com>
To:  ken
Date: Sunday, July 02, 2000 10:28 PM
Subject:  Thank you from donor mom

Thank you for your wonderful letter!!!!!!! !!!! !!!! I received your letter upon my return last Sunday June 25th from the U.S. Transplant games held in Orlando, FL at Disney’s wide world of sports. I was a part of Team Philadelphia, participating as a donor family along with five other donor families from the Philadelphia region.

Although Christopher’s organ recovery was coordinated by the Sharing Network of New Jersey as he was airlifted to Cooper Trauma which is a part of their coverage, I am actively involved with the Gift of Life Donor Program in Philadelphia.

I can never express how very grateful I am that you responded to my letter, I have prayed for a reply for a very long time now. I am glad that you are doing well. I have visited your web-site, and found it informative and inspiring. I am glad your recovery is successful, and understand the long process and the road ahead for you.

I have been told that both of my grandfathers were alcoholics, and my father now 74 years of age has been sober for 18 years this coming October (after 35 years of drinking), and my brother now 49 years old has been sober for 19 years after about 13 years of drinking). Also, Christopher’s dad (my ex-husband of 13 years) is an alcoholic, so I have some idea of the hurdles you have faced, and I congratulate you for your persistence and conviction to recovery. As the road ahead may be full of challenges, I am certain you will overcome each of them one day at a time.

I loved the photos of your garden on the web-site, Christopher would be proud. My garden isn’t doing as well as I had hoped with the very warm weather this summer, I moved to a condo in Jan 99 planted flowers, but they were all wrong as it only gets shade. So I started over this year, it’s very slow going, but I am certain my angel will keep a watch and help it along.

I hope you have been able to do some fishing this season, Christopher liked fresh water fishing in the Delaware, and in a few local lakes. He only went salt water fishing once, on an uncle’s boat for the day, which he enjoyed very much. It was very difficult as a single mom to learn to fish, but Christopher and I were getting there. HA-HA:>):>)

I love the part of your web page dedicated to CRS, Christopher Russell Steinmann 11/7/83 – 5/22/97. Thank you, I am proud of your handy-work.

I would love to hear from you again.
Christopher’s mom
7/2/00

From: KEN
To:  PCOLVELL@email.msn.com <PCOLVELL@email.msn.com>
Date: Monday, July 03, 2000 4:17 PM
Subject:  Thank you for responding
Dear Pam,

Thank you for responding. It was a great surprise seeing this in my e-mail. I wondered often when and if you would respond. I also was a great relief to know that you understand about my alcoholism. I often wondered how that might effect you. I was afraid that you might be judgmental as so many people are. I was asked to speak and behalf of the hospital at one point last year, but I was asked not to mention why I was in need of a transplant. For some reason that just didn’t sit well with me so I denied. I asked for them to find someone that was better equipped to speak to the public. I’m not ashamed of what I am, the way I perceive it is “What I am today is God’s gift to me, what I do with it is my gift back to God”.

It is kinda ironic that you went to the games in Orlando, I was thinking early this year about going to them. But I had a Hernia repair surgery in January and was concerned about being healthy enough to participate in the games. Everything went well with surgery and would have been able to participate. But better safe than sorry. God willing, there will always be next year. I would also like you to know that everyone I come in contact with and everyone that has visited my Homepage, I ask them if they are not already, to become a donor.

As I said earlier, it was a pleasure hearing from you. I also appreciate the additional information you gave me about Christopher. It is a great relief knowing his full name and yours. Please feel free to visit my Homepage again. Now with information I will have to update it. I like to keep family and friends posted. If there is anything I can do for you within the “Gift of Life Donor Program”, please feel free to ask. I would also like to know if some where down the road the 2 of us could meet in person. Maybe this is too much to ask, but I feel like this would be great. This seems strange but I was born in Bergen County, Hackensack to specific. Thought that might interest you, with you living in Edgewater Park. Thank you again....

From: PAMMYC <PCOLVELL@email.msn.com>
To: Ken
Date: Friday, July 07, 2000 10:54 PM
Subject: God’s gift

Thank you for the wonderful words of your perception “What I am today is God’s gift to me, what I do with it is my gift back to God”

I have been thinking about these words for several days now, God gave me so many wonderful gifts, most importantly the love of my son, I try to give back as much of that to God as possible. Hence my active involvement with the Gift of Life Donor Program, and spreading the wonderful gift of donation.

I am glad you have recovered from your surgery, and are doing well. The games were a wonderful experience for me, seeing just what a WONDERFUL life recipients can and now live, they value each day of their new life. It has taught me to step back and think about my life and what I can give to others.

Ironically, in April 1989 when Christopher was 5 he wanted to explore Cape May diamonds, so we drove to Cape May for that reason on the way we discovered the zoo there, we had such a wonderful day that we made it an annual event on the Saturday of Easter weekend. I haven’t been there since we were there in 1997, I would love to return but am very apprehensive about it. You are so very
lucky to have such a wonderful place to visit. I still have the first Cape May diamond (a milky white stone) he found that day. Strange the things moms keep.

I would very much like to meet you; I am so overwhelmed at the possibility. Perhaps one Saturday or Sunday that could happen. You are always in my prayers.

God Bless
Pam
7/7/00

From: KEN
To: angelicmommy@hotmail.com
Subject: Angel Story
Date: Wed, 05 Jul 2000 01:39:59 EDT

Hi Pam, Ken again. I hope it is alright to call you Pam. I feel kinda awkward calling you that. It sounds improper to me. Sorry, just thinking out loud. I have a link you might be interested in seeing. This tells my story in detail a bit further than what you might know. I sent this in originally as an entry expecting nothing to really come from it. But much to my surprise, as many things are recently, it was picked up by the web site and put on it’s own page. I hope the story isn’t too informative. But after receiving your letter back in March. I’m not sure even if I told you that. I didn’t get your letter until March of 2000 and I think you mailed it out in August of 99. Well, I felt a need to start telling my story, as well as Christopher’s and yours. I just felt a great deal of Gratitude and wasn’t sure which way to channel it. AA is a big way of carrying the message but I felt that I needed to do more. After this story ran for a week or two it was picked up by another site, with my permission, of course. I’m trying to get a copy of that one too. When I do I’ll forward that also.
If this is all too much for you, please let me know. I wouldn’t want to overwhelm you. You have no idea how much all of this means to me. Right now as I’m typing it is 1:34am, I was lying in bed and felt the need to get up and do this before it was all fresh to me. Once again, thank you.

Ken

(Note: notice the time lapse in the letter communications mentioned above. Pam wrote hers to the OPO August of 1999. Her recipient received in seven months later in March 2000. He responded immediately but she didn’t receive it until late June of that year. Understand that this process is not a normal mailing cycle, so don’t get impatient in the waiting, realizing that it may never be received, as is the case in her first two letters from ’97 and ’98)

From: KEN
To: PCOLVELL
Date: Wednesday, August 02, 2000 9:19 PM
Subject: Birthday Gift!!!!

Hi Pam,
Thank you so much for the birthday gift. I must say it came as quite a surprise to me. I will wear it with pride. Your kindness continues to surprise me. It was very thoughtful of you to send the hat, what even surprises me more is that you were able to pick up out of my e-mail address that 8-6-64 was my birthday. It couldn’t have come at a better time either. That particular day I was expecting birthday cards from my family and disappointed to find none.
there. Your envelope was on the bottom of the pile. That brought me right out that moment of self-pity. I even shared in my AA meeting that night that God continues to put people in my life exactly at the right moment.

I wanted to also thank you for sharing my letter and Homepage with your Daughter. It was a pleasant surprise to see that she had signed my guest book. She seems to have a very good head on her shoulders. She also surprised me with all the wisdom that she has. I wish her well and hope she continues to grow from others experiences, good and bad, through her life.

Once again thank you and I hope all is well with you and your family. Take care and God Bless

- Ken

Date: Tue, 08 Aug 2000 16:42:25 EDT

Hi Pam... I’m sorry to say that I’m not on the mailing list for that newsletter. I was supposed to be put on several times by the Social Worker at UMDNJ. Every time I talk to her she said that she has added me to the mailing list but as of yet I haven’t received one. I really would appreciate it if you could add me to the list. Also if you could send me a copy of the recent newsletter I would appreciate it even more. If you’re unable to send it, I would really like it if you could send me a photo of Christopher. I was going to ask you sooner but it just never seemed like the right time. I would mean a great deal to me if you would. If you send the picture, I would like your permission to add it to my Homepage.

It was a pleasure hearing from you again and I too look forward to meeting you in the near future also. God Bless and stay well. . .Ken

From: KEN
To: angelicmommy@hotmail.com
Subject: Re: Newsletter
Date: Wed, 09 Aug 2000 22:31:08 EDT

Hi Pam, Thank you for adding me to the list. I also visited your web site. It was real touching. It is a little tough to explain. I knew of him and I knew what he liked, but until I actually saw the picture. I don’t know, like I said, it is tough to explain. I’ll try though and please don’t take this the wrong way if something comes out wrong. This is coming from the heart and not from the mind. When I saw the photo, I felt so sorry for your loss. Such a good looking young man and his whole life taken from him. Then I felt really unworthy of his gift, and I know I shouldn’t. But when I look back at my life and see the damage I caused myself and others, it saddens me to think that your son had to lose his life for me to continue on with mine. I don’t ever want to question God’s will for me and others. But sometimes I ask myself “why me and why Christopher?”. I hope this isn’t upsetting you, because that is not my intention. I believe in my heart that everything happens for a reason. But sometimes life just seems unfair. I know today that the rigorous honesty with myself and others helps me grow spiritually. I just thought that if anyone could understand how I felt that you would. Once again, please don’t take anything I said the wrong way. I cannot even begin to repay my debt to you, your son, and God. I am truly Blessed and grateful.

I also updated my homepage, I hope you don’t mind but I used the photo from your web-site and put it on mine. I also added a link on my homepage to be connected your web-site in memory to Christopher. I hope that is okay with you. If it is a problem, let me know and I will change it... .Ken
From: Pam
To: Ken
Subject: Re: Newsletter
Date: Wed, 09 Aug 2000 00:58:23 EDT

I will give info for your name to be added to mailing list; will try to get a copy of last newsletter.

I have started working on a web site in Christopher’s memory; it is very much in progress. www.homestead.com/DONORMOM522

(Web site poem:
To my son, whom I will love forever
I gave birth, you gave me life and breath.
You taught me patience, kindness, and love,
and gave me laughter and joy.
Your life was taken away,
then you gave it back to three.
You hold a forever place in my heart,
every proud moment, every happiness,
joy, love, and laughter you gave to me
are tucked away with love.
Thank you for being my wonderful,
loving son. I will miss you always

Love Forever
Mom

Christopher Russell Steinmann
November 7, 1983 - May 22, 1997

Let me know what you think.
Pam (I would very much like for you to call me Pam)

From: KEN
To: angelicmommy@hotmail.com
8/12/00
Subj: Donor CRS

Donor CRS
Submitted by: Ken, March 02, 2000

This is not an easy thing to talk about because a lot of people are judgmental of me and people like myself. I am an alcoholic in recovery about 5 years ago I was diagnosed with Cirrosis and it progressed rather quickly. By this time because of my active alcoholism I was without a job, without a wife and without money. But thank God for family. At the age of 30 I was forced into moving back in with my parents. Needless to say I was a burden to them and not to mention myself. Although being diagnosed with Cirrosis I still did not stop drinking. My thinking back then was, why stop I’m going to die anyway and previous attempts at getting sober failed. Not that the program had failed but I had failed.
It wasn’t till one day after being released from the hospital and being told that my Liver had shut down and that there was nothing more that they could do for me. I was to go home and wait to die. I left that hospital and drank again. But this time something happened. After drinking and passing out in my bedroom while my parents and grandmother were away, I came to with a feeling of Peace, Calmness and Serenity. I knew at that moment it was over.

Today I know it was “The Grace of God” that took the drink from me. I for the first time in my life realized that alcohol was no longer to be part of my life. The rest of the story is where I believe God and his Angels carried me. I had accepted the fact that I was going to die and I was ok with that, as long as I could die Sober.

Days turned into weeks, weeks turned into months. I had become a patient at a Liver Transplant Center. Although they were helping I was told that there would be little chance of being transplanted because of my financial circumstances and my Alcoholism. One year had passed and I was put on the list. I really saw no hope in my situation. Then 3 months later the phone call came, I was to report to the hospital, I was to be the back-up to the back-up candidate for a transplant.

On that day May 23,1997 I received my Liver and that’s when my Angel saved my life. The reason I’m writing this letter today, March 2,2000,I received a letter from my donors mother. She told of her son and how she loved him. She divorced was he was 2 and for that reason they had an incredible bond. Although he was only 13, he had a great love for the environment and a understanding for recycling. This confirmed his mother’s decision to donate all his organs. I only know him as CRS, I do believe that he is my Angel and I believe that God does work through people. His mother’s selfless act of kindness brings tears to my eyes and joy to my heart.

CRS, my Angel your life lives on through me. God Bless You and Everyone’s life you have touched. I know you Saved Mine!!!!
I will do my best to put this into words. I have been jealous of donor families who meet their recipients and have such a wonderful bond. I had a very difficult time at the games knowing they were there to cheer-on their recipient, I realize we were all there for the same reason, it just tugged at my heart strings knowing they had a “stronger” and “different” connection.

Returning from the games to receive that letter just took my breath away, I remember standing in my kitchen when I returned home at 4a.m. and reading those words and then taking a few days to really click. I was so excited yet when Ken asked to meet I held him off because I then wasn’t certain I was ready. Ironic after all this waiting and anticipating a meeting.

As you know I have been communicating with him via e-mail daily since June 25th. Then chatting with him on-line several times I began to feel more comfortable about a meeting, so I put it out there to him several weeks ago, and we agreed. That was the like climbing the first hill of the roller coaster as the gears grab the cars and click as you climb for the descent, then we had arranged to meet on the 30th of this month and he sent a message he needed to change the date, I thought I was on the down hill side of the coaster at that point thinking he was now putting me off. However, he need to change the date because he doesn’t have a driver’s license and needed his dad to drive him and they will be away on vacation the 29th of Sept to Oct 10th.

A few days later I received another message to set another date – click, click of the second upward hill of that roller coaster and now my heart was definitely pumping. We agreed on the date for today and the adrenaline starting pumping on the second hill downward.

I went to 8:30 church service today having a difficult time concentrating and yet wondering if I was doing the right thing. I hadn’t told any of my family about this meeting, I didn’t want any of them trying to talk me out of it. Driving in the pounding heavy rain I was beginning to doubt our meeting and wondering if I should turn around and just go home. A song came on the radio, the song that played the day I was driven home just after Christopher was pronounced dead at the hospital, a sign, I am certain. I continued toward Cape May. Approaching the road to Sunset Beach our meeting spot, the skies cleared and the shine shone, I was certain Christopher was with me and that this was definitely the right thing to be doing. This the giant turn in the roller coaster just before you make the small drop before the final upward pull to that last stomach wrenching decline.

I drove through the parking area, there in front of me was an open space (another miracle on this day), I park my car as my pulse race and my heart pounded. One last quick pray and chat with Christopher and I got out of my car, looking straight ahead I saw a man looking very much like the web photo. I asked are you Ken? He then handed me a dozen white roses. We hugged, and hugged, and hugged as we cried together, sharing our common bond with one another, I think we could each feel one another’s heart racing.

We both knew this was a monumental and memorable day, you could feel the release of anxiousness, and nervousness from both of us. We each admitted just how nervous we were about this meeting and were able to again hug and soothe one another’s anxieties and frustrations. I had now gone done that last hill of the roller coaster.
We decided to go to the point and visit the lighthouse and watch for the butterflies on their migratory pattern. We saw many butterflies, in fact several species, but mostly monarchs, their beautiful black and orange colors reminding me of Halloween, we both spoke those words in unison. As we stood there watching he asked what I was thinking, as I came out of that fog, I expressed the story of the butterflies and my friend Jim as he tells it.

Suddenly, we were crying and hugging again. I could feel Christopher there with us, and we began talking about “things” that changed for him after transplant, he attributes them to Christopher’s character, perhaps some of them but not all.

Then we went to lunch together, driving in my car looking for something open for lunch in Cape May became a challenge. We drove on to Rio Grande and found a lovely little restaurant open, an old train station conversion. We spent several hours conversing about him, me, Christopher, and our feelings. I held my own until he expressed that he has a much better relationship with his mother now and he attributes that to what he now knows for certain is the “wonderful bond you and Christopher had”. My heart was touched, and tearing once again, yet it was helping me to heal.

We left and I drove him home, upon arriving I met his parents and his 92 year young grandmother who each hugged and cried with me. I was feeling overwhelmed with gratitude and love. Yet, they told me I was soothing them in meeting and allowing them to express their feelings. Ken’s dog Pete which he had warned me doesn’t usually take to strangers became a fast friend. Amazing – it was like this dog knew some how. Although they invited me to stay for dinner, I needed to leave for the long ride home.

Ken walked me to my car, we hugged again, I found it very difficult to part, I felt as though I were leaving Christopher once again. As I drove away I saw Ken drying his eyes once again. I stopped a few blocks away to regain myself to be able to drive home, I was emotionally exhausted yet exhilarated by the feeling of warmth and love I received. The ride home was very spiritual. I knew Christopher was with me and thought of nothing but him and our relationship with one another and how very grateful I am for the wonderful bond we had and still have in another dimension. Now there was a new bond with Christopher through Ken.

Now I say good night.

Pam

That same night when Pam returned home from this Cape May meeting, she just had to tell someone all about it who would understand. We had worked together for the past year, volunteering at the Gift of Life Donor program, and had developed a close friendship among several of the core volunteers and OPO staff. I was overwhelmed that she choose me to call with the bursting emotions of the event. We cried together on the phone. Later, when I received her e-mail story above, I e-mailed back the following:

From: GleasonJim@aol.com <Gleasonjim@aol.com>
To: PCOLVELL@email.msn.com <PCOLVELL@email.msn.com>
Date: Sunday, September 24, 2000 10:57 PM
Subject: Re: feelings
Wow, you express your inner self so beautifully (as I hoped - yes, and knew - you would). Pam I feel so happy for you. Your reunion with Christopher (through Ken) was just waiting to happen, and now it has - and so beautifully - sunshine, butterflies and all. I read your lovely sharing very slowly, savoring every emotion as you described it so well. Using the roller coaster analogy was perfect - so “Pammy”. My heart went out to you - it was there every “click” of the way with you, and now it knows so much better what you went through.

I know you will never “get over” (such terrible words - definitely not my words) your loss - but you are definitely “healing” with each passing month (with Christopher’s help), especially with your involvement in our programs, with our personal hugs (I so enjoy with you), and now this “reunion” with your recipient like this. I could never have imagined the feelings you had at the Games as you described them. Knowing that now, I am even more pleased that we were able to share the time we did at the Games, offering, I hope, some solace in being your “adopted” heart there to offset some of those longings. As I have shared before, things seemed to happen there that were so much more than chance - much like your experiences today. That’s another thing that you and I share - based I think in our Christian faith and belief in a life after this. That bus ride at the Games returning from the donor recognition event - holding hands as we did sharing emotions of that beautiful event - was orchestrated beyond ourselves. A very beautiful once in a lifetime moment of sharing from deep in both our hearts.

Pam, I am so happy for you, and again thank you for opening your own heart in this sharing of such a private moment. I wish you a night of beautiful and restful dream filled sleep. You so deserve it...

With love and support,
Jim
9/25/00

Ken wrote in his e-greeting card later that same evening:

9/25/00
A greeting from Ken, especially for Pam:
Thank you
Thank you Pam for a wonderful and memorable day. It is something I will not forget anytime soon. It was a pleasure talking with you and letting you know a little about myself. You were so easy to talk with. You made the whole experience so much more relaxing. I hope to do it again soon.

God Bless Ken

By way of summary
You are probably wondering what has happened since that meeting in 2000. Here’s a brief update on Pam and Ken since then.

Since that first meeting, Ken and Pam have not met again face to face again. Ken announced his wedding plans several years later and invited her to attend that event down in the islands. She offered her thanks but did not accept and is very contented with the mutual sharings they both have enjoyed. Today she still has all those OPO letters and e-mailings together in a folder.
Included is Ken’s wedding photo, looking very happy with his new bride standing in the island’s sunset.

No note has ever been received from that other kidney recipient out in Pittsburgh, PA.

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In conclusion
Some asked about my own donor communications and meeting experiences. You will find in Section 1 of this book, in my own story there, that answer. Throughout the chapters I have shared my annual letters of thank you to my donor family, hoping to encourage you to write your own donor family. As for meeting face to face, yes, I have been blessed with that too when my family arranged for a surprise meeting at the 2002 US Transplant Games in Orlando Fla near where my donor’s family lives. In Chapter 27 of this book, on the Transplant Games, there is the story of that meeting with my own donor family in July of 2002 (see pages 28 through 32 of that chapter – with photos of everyone too!) at the donor recognition ceremony there. That story is also shared on the web - just link to www.Transweb.org and search on “Gleason Surprise Meeting“.

So now its up to YOU
I hope that this very long chapter has been an enlightening, entertaining and educational reading for you. I certainly have enjoyed compiling everyone’s contributions that made it possible. While I had read those e-mails when first received, mostly back in the 1999 timeframe, it was like reading them all new again when I finally got around to putting this chapter together here in April of 2005. There were many special memories and people who opened their own hearts in writing as they did. My heart goes out in thanks to each and everyone who both shared their stories and experiences in this very unique way, but also for their long and loving support of this project that took so many years to finally come to fruition.

A special note of thanks to Faith Carlin, a kidney/pancreas recipient, for sharing her donor family meeting and contributing the story and articles that documented that experience.

And in one final very special thanks, my heart reaches out to Pam, a donor mom who allowed us all to share in her story and emotions over the years of her donor family experiences in communicating with both the OPO and her recipient. Pam has given so much to so many in her working with the both Liaisons for Life and the Hearts of GOLD volunteer arms of the Gift of Life Donor Program, creating their first Threads of Love donor memorial quilt, providing guidance and support as the NKF Donor Family Liaison for the US Transplant Games, as well as countless hours of one-on-one support to donors and recipients alike in loving memory of her son, Christopher. “Thank you, Pam.”
PS: See a still later addition to this topic as the end of this chapter below….

Sincerely and with HEARTfelt thanks,

Jim Gleason
275 Green St, unit 4M3, Beverly NJ 08010
(610-999-0341)

I hope this sharing will help you face your own challenge. It is my way of thanking you who helped in so many ways. Want other monographs from this series? Contact me at the above address/phone.

May 2007
One of our readers asked if she could still add something to this topic. Given the nature of “virtual publishing” I replied, “of course…” and this is what she so beautifully shared in response to my sending her a link to this chapter:

My Oh My Jim!
After reading a few letters in the link you sent me,.. I had to stop for a while, but will go back to it after I recover! I started crying and had to stop for a breather. This is a very emotional issue yes, but it really does help to see others experiences and get a feel for the donor family side of things.

I don't know if you are continuing to need articles and opinions on the transplant recipient experience, and contact from the donor families, but may I share mine with you?

I received my heart on November 22,2006. After 4 years of waiting, it finally came. After 5 false alarms, the 6th one was it. All I knew at the time was that my heart came from California. That is all I knew. When I woke up, I knew immediately I wanted to contact my donor family, but the Lifecenter Northwest did give us a brochure on a few guidelines when writing the family. It was a very helpful tool indeed for me,, and I did my best to follow it. I went home a couple weeks before Christmas. Since it was right before Christmas,, I knew I should wait until after the holidays, so I would not intrude on my donor family's grief. I waited until about mid-January and wrote my letter. Lifecenter Northwest does tell you that you may or may not ever hear from the donor family, but that was a chance I was willing to take. I had to at least send my thank you for giving me back my life. Writing that letter was one of the hardest things I have ever done in my life. I knew I had to at the least, thank the family, for my own peace of mind.
I waited and waited what seemed like forever,.. it was only 2 months. I wrote a second letter,.. and the day after I sent the second letter, I received a response.

My husband checked the mail, and when he came in the house, he sat down at our kitchen table, he said to me, "What the heck is Lifecenter Northwest?"

I was in such shock, I froze. He handed me a manila envelope, and as I opened it,.. I started crying and it got worse. I started shaking, and crying uncontrollably, and he got scared. He asked me if I was ok, and if I really was ready to read this mail.

I put it down, and drank some water trying to calm myself down. I picked up the letter that was in a plain white envelope. As I opened the envelope, I could tell there was a photo in it. Well, the flood gates opened again,.. I saw her. Without reading the letter yet, I could tell it was her. The photo was of a woman and man with their arms around each other at the beach. It was taken 2 months before her death.

My husband tells me I had ESPN (he is a smarty pants)because I just knew she(Sara) was the donor, not her husband Paul.

I had a hard time reading the letter, but then I read it over and over, and over. It was as if things had finally come full circle for me. That was the last question to be answered for me about the whole transplant process.

Here is my donor family letter. Every one who has read it so far, has been brought to tears. It is so beautiful, so gracious, and made me feel so good.

Dear Peggy & Family:

My name is Paul, and I am the husband of the wonderful woman you received the donation from, Sara. I received your letter a few weeks ago, and have been trying to think of what to say about Sara. I am overjoyed to hear that Sara's heart is beating strong, and that you will get a chance to live a long and happy life with your family. It gives both me and Sara's family great comfort to hear these things.

So, what to say about my beautiful Sara? She was 29 years old, with naturally curly blond hair and a real zest for life. She had brown eyes, cute little freckles on her nose, and the whitest clearest eyes. She always seemed to be smiling and had a great sense of humor. Also, she was without a doubt, the most sarcastic person I ever knew.(In a good way)I have included a picture of us, so you can see her for yourself. She grew up on a farm located east of Toronto, Ontario, Canada. She was 1 of 5 children to two loving parents with three brothers and one sister. Sara was the middle child, with 2 older brothers, so she spent the early years of her life competing with them. This inner drive would shine through for the rest of her life.

Sara and I met in high school, in the spring of 1994. We were together through high school and college, where she studied business and math. In 2001 after college, we both moved to the Bay area in California to pursue our careers (and get away from the snow!)

You will be happy to hear that Sara was a very happy, healthy person who enjoyed hiking, running and tennis. She played varsity women's rugby in college and was a gymnast. She had no major illnesses, was not on any prescriptions and had never spent any time in the hospital. She was in great shape, and had just recently run a 10k marathon. Needless to say, Sara had many talents. Her favorite pastime was baking, which seems to be a great fit with what I have been told about you.

Sara had a real zest for life. She had a real energy to her,.. almost electric. Obviously, you are more aware than most of her generous nature. She was a regular blood donor, and had been a strong supporter of organ donation since her early teens. She used
to give me a hard time about it, as I was on the fence about it. Not morally, but I was a bit squeamish about it. I am now proud to say that I and Sara's entire family are organ donors. I know that Sara is watching as you read this, and is very satisfied to know that she was able to give life to someone like yourself.

Now, surrounding the circumstances of Sara's passing. This is the most difficult part of the letter to write, but is important for your own peace of mind. On November 19th, 2006 Sara and I were camping in Southern California. That morning, she awoke with a terrible headache, which got worse very quickly. As Sara was literally never sick, we headed to the hospital to check it out, as she was getting worse by the minute. At the hospital, she was diagnosed with a cyst in her skull that was in just the wrong place. It was blocking the spinal fluids that are produced in your skull from draining properly into her spine. The pressure was building quickly, slowly crushing her brain. Unfortunately, she did not receive the proper treatment in time and she did not recover. She was officially deceased on November 20, 2006. Her parents and siblings all flew to California to be with her while the donor arrangements were made.

Well Jim, any Kleenex left? This was the most gracious letter I have ever received and am in continued contact with Paul. I have also been in contact with Sara's sister. Paul is flying here to Washington the first part of August, and we plan to meet. I never believed that a family losing a loved one could be so loving and accepting of a total stranger. Sara's sister Katy, and I e-mail each other weekly, and it is almost like having another daughter. This has been a strange but most wonderful experience for me and my family. I highly encourage people to write their donor families. Yes, the possibility of never hearing from them does exist, but the advantages of contact are so worth it.

Good luck with your future writing, and if I can be of help or contribute in ANY way, please ask. I look forward to reading more from you, Thanks for 'listening' to my story here.

- Peggy

And in yet another sharing, Steve wrote:

Here ya go, Jim. This is the post in full, from February of '06. I hope you find it useful.

This is a post I made to another group earlier this morning; it's an emotional subject for me, and it took me a couple of nights to get through writing. I'm posting it here because the subject is relevant to this group also. It was written primarily in response to a donor family member who's been a bit disconsolate; she's heard nothing from the several recipients of her husband's organs, not even after writing *them*. I know how hard it is to write that letter, and thought that this post might be of some small assistance to those here who might be feeling the need to write but haven't yet been able. I'd never encourage anyone to do something that they're simply not ready to do; that's not the purpose of this post, but if you
I've been following this line of discussion attentively; it's a subject that sometimes comes up in the transplant group that I help moderate, and it's generally written about with great passion. I'm sorry that I got to replying so late in the game.

Prior to my transplant, I sat through several meetings of the brick and mortar support group and listened to the stories about writing those letters. I was always a bit of a skeptic when folks talked about how tough it was to write that first letter. After my transplant, I had a bit of a different perspective; the other stories I've heard are much the same, in that writing that letter is one of the hardest, most emotional things a transplant patient can do.

I'd had my transplant for about four months when I started to feel the need to start writing; I'd heard several times about the recommendation to wait for a year before initiating contact, and while I understood the reasons for that recommendation, I really needed to at least start putting my letter together. I started to put it together for two months; if my drafts were made out of paper rather than kilobytes, I imagine I'd have thrown out about a room full o' paper. I'd included facts, figures, and perhaps everything but a bibliography. I was frustrated to no end, because nothing was coming out right.

I was at the support group meeting one day when the subject arose; it turns out more than one person was having that problem. I didn't really chime in, and barely took notice when another guy in the group said "Just write it from your heart". I wasn't until I got home that I *really* thought about that, but the thought that came to me was "Just write it from your donor's heart". The letter that I eventually sent took me twenty minutes to write from start to finish.

I know some of the stories mentioned here, about negative experiences after having written that letter are true; I received the same cautions in my support group, and I've in fact heard similar stories from some friends of mine. In my case, though, the experience proved to be cathartic, in the writing, and an unbelievable blessing in the reply that I received. I got the reply about two months after I gave the letter to Life Center Northwest (the Organ Procurement Organization in my area, and the organization with primary responsibility for Donor - Recipient relations). I was sick with a rotten head cold that day, and I needed some encouragement...hoo boy, did I get it. I picked up the mail at around 5:15 in the afternoon, and when my girlfriend at the time got home, about fifteen minutes later, I'd read it about thirty times. She walked in, saw me sitting at the couch with tears running down my face, and before she had a chance to ask me what the matter was, I simply said "His name was Tom". She understood immediately. Tom's
wife, Kristin, had written; she told me, among other things, than my letter had validated the hardest decision she'd ever had to make on what was the hardest day of her life, and that her decision was the only good thing to come out of that day. She said that, much like happened when I read *her* letter, that when she saw mine, she'd sobbed for hours, from grief for Tom, certainly, but also with a sense of fulfillment and completion. I wrote her again some time later; in her reply to my second letter, she said that she and her kids were having a rough time, and asked for some time. I've given her that; I hope that we can one day get in touch again, but in the meantime, she knows of my gratitude and my love, and she knows the name of the person in whom Tom's heart now beats. I'm really not sure how I could ask for much more than that.

Writing that letter was agonizing; it brought up feelings in me that I'm not sure I want to feel again in my life, but the person to whom I wrote it *saved* that very life. I felt then, and feel now, that I owed her that thanks; Tom, you see, is a very special hero to me for obvious reasons, but the *real* hero, in my eyes, is Kristen; *she* had to make the final decision, and *she* has to live with the memory of making that decision while knowing that her husband's chest was still rising and falling with his breath. I can't even conceive of the courage and the love that it took to make that decision.

I've thought long and hard about what I'm writing tonight, and what I'm posting with this email. I'm including a link to the letter I wrote. Part of the reason is probably for you, Cheryl. I'd like for you to have received a reply to the letters that you wrote, and though I think you should have, I also know how terribly difficult it is; I know some very good people who are years removed from their transplants...people who'd give anything to write that letter to say thanks, and simply can't bring themselves to do it. They know, though...they know that without people like you, like Lori...and like Kristin, that they wouldn't be here. They're more grateful for that than you may ever know, but some of them are just so grateful that...they just can't say it. This letter, then, is for the donors and their families; it's also for the folks that may be having trouble saying thanks; it's a hard thing to do, and as has been mentioned several times in this group, the reply you get, if any, isn't always gonna be what you want to hear. In my opinion, though...and I can't speak for anyone else...it's worth it, just to give those thanks.

http://home.comcast.net/~unclfester/letter.html

The thing is, Cheryl, you *are* someone's hero, whether they've told you that or not. You're certainly a hero to me, as is Lori, and as is Kristin. Thank you...to all of you...for what you had the love and the courage to do.

Grace and peace,

– Steve
May, 2008:

As a member of the NKF’s editorial board for their donor family newsletter, For Those Who Give and Grieve, I had offered a topic and accepted the assignment to author it on the subject: “Why Didn’t They Write...” – based on insights from transplant patients. Reaching out to the many web based transplant networks I contribute to, I solicited their answers to this question as input to the article. While it is always edited down for a newsletter, which appeared in their Spring 2008 issue (see photo here), I offer the full version as originally submitted (with special thanks for all those who responded to my request that they share their reasons for not writing....) as a final piece for this chapter, hoping that it will help you to write that letter you may be needing some help with as you read this.

The article as it appeared received great reviews and was even requested for reprint in some OPO newsletters, another indication of the importance of this topic in the transplant world.

Full original article:

“Why didn’t they write?” – patient insights...

by Jim Gleason, heart recipient (13+ years out)

(optimal lead in ….) In my favorite transplant love story movie, Return to Me, there is a touching scene dealing with the difficulty many transplant recipients experience in writing that thank you note to their donor family. In this scene, Grace, the heart recipient (played so perfectly by Minnie Driver), is still torturing herself about actually mailing the letter she has written and been carrying around with her since receiving her new heart a year ago. Her sister (with five small kids in tow) offers her the encouragement she finally needs to so tentatively drop that letter into the nearby mailbox there at the zoo (where, coincidently, her donor’s spouse, played by David Duchovny, is working and they come into contact for the first time). While this may be just a movie fictional story, it does accurately capture the difficulty many recipients find in expressing themselves after a life saving organ transplant.

(end of optional lead in)

Reaching out to a sample of recipients, I asked for insights as to why patients hadn’t written to their donors, at least to express a simple thank you. The response was not overwhelming, indicating I hope that most actually do write, but enough replies came back to provide a realistic insight into that lack of communication. But lets be reminded up front that both sides of this gifting process understand that neither is under any obligation to communicate, accepting that it is an anonymous giving and accepting. That said, human nature being what it is, there is often an expectation by donors of some acknowledgement and a corresponding interest by some recipients in knowing something about the donor. But given the process, neither side knows enough about the other to be able to understand what to expect or what is acceptable, and thus lies some of the basis for the insights shared in this
too brief article, reasons which are as varied as the parties involved in the issue overall.

Reason #1: **Perfection/inadequacy** - Most write, but either rip it up as not being good enough, wanting it to be perfect, not being able to find the “right words.” Tony shares: “I haven't written to my donor family cause I just don't know what to say. Words cannot describe how thankful I am to them for giving me a second chance at life! That was a miracle itself! It is overwhelming to me at times cause I wouldn't have my daughter either! There are no words that could express my feelings for saving my life and giving me the child I have always wanted! I am forever grateful” I can hear you thinking as you read this, “But she just did say it!” Or as Ken, a liver recipient one year out, put it simply when he finally did write: “You never received any of the other letters I previously wrote, because I was left feeling none of them were good enough to express my feelings reasonably well. This attempt may not be as good as I would wish, but I feel ashamed that so much time has gone by without a word of acknowledgment or thanks from me. If I continue to keep striving for perfection it will delay the message to you even longer.” So while an often cited professional or friendly advice “to just write it from your heart” empowers some to overcome this “never perfect enough” concern, saying that isn’t the same as actually doing it, which leads to the second most common response.

Reason #2: **Fear** - Even once written, actually mailing it (as in the movie) is still a big challenge for many, mostly out of fear of causing pain to someone they feel so grateful to for this ultimate life saving gift offered at a time of extreme tragedy for the donors, and it is recognized that that donor is often the living person who said yes to the donation request, the one who will be reading the letter. Here is where that fear of the unknown comes to play, not knowing the family situation of the donor family, are they ready to hear about where their loved one’s gifts went? Will such a note bring back all the pain and grief felt at the time of donation? And then we have the choice of words, not just the “perfect” words, but the expression of that gratitude, reason #3.

Reason #3: **Grief vs. celebration of life** - As Pat wrote: “...there wasn't any way to say how grateful I felt to have gotten this chance at a normal life with my big, ever-so delighted family without feeling that hearing all our good news would cause sadness and hurt to the donor's family.” This was repeated in many variations as this from Sandy affirms: “As the years rolled on, I found it much harder to write, because now I didn’t know what to say. I was still equally excited, but felt as if I was saying look at me, I am doing great, while your loved one is no longer here.”

Reason #4: **Privacy** - John is one who did write shortly after his transplant, and received a loving response, would like to write again but hasn’t since out of respect for the donor family’s privacy, not wanting to intrude further on their lives. As many shared, Richard too wrote, but tore it up many times, even though wanting desperately to hear from the donor. Instead he keeps the thanks in his daily thoughts and prayers for the donor and their family, never actually finishing that note out of respect for their privacy.

Reason #5: **Ignorance** - Not as common with today’s education and support for writing, but cited by some long term transplant survivors such as Eddie, who got kidney transplants in ’71 and ’80, such communications were not encouraged and he got little if any knowledge of a process by which such a note could even be given. Eventually such patients acknowledge feeling it is too late and reason #2 comes back into play, not wanting, as Joan, a long term liver
recipient said, to “reopen wounds” for the donor’s loved ones, not knowing if that is a widowed spouse, child’s mother, loving sibling or whomever.

Reason #6 – **Protective oversight** – From a “new heart family” we see another roadblock when “…in 1985, I wrote a heart-felt note to my donor family. Many years later I discovered that the letters are screened by the hospital staff and they can decide not to send it without letting the letter writer know.” This can also be well intentioned OPO staff making protective judgments based on their direct contact with the donor or patient family. I have also known donor families who have hidden recipient letters from a loving mother out of protective concern, only to find that “discovering” one such letter years later, she was open and thankful for that message, eventually asking for a meeting with the recipient.

Maybe the best advice for patients in overcoming such reasons can be found in the following insightful sharings from Steven and Robert (among others), heart recipients, who wrote similar words (merged together here...): My Coordinators told me to just be myself and write from the Heart (pun intended). I wasn’t sure how to do that, but after more false starts, I finally sat down one afternoon to write the note and I told myself that no matter how it came out I would send it. I decided to write it with pen instead of typing as I thought this more personal. I did mail the letter and have never heard back from them. And, after many, many false starts we hear another’s variation on this: …but the thought that came to me was "Just write it from your donor's heart". The letter that I eventually sent took me twenty minutes to write from start to finish. You would think that deciding to write a letter would be an easy task compared to the decision facing the donor family and at the worst time of their lives. Sometimes we need to look at the big picture. Fortunately we as transplants get a second chance to do just that.

But then, maybe things haven’t really changed much in 2000 years when we recall how in the bible story about Jesus healing the ten, only one comes back to say thanks. But my experience tells me that our numbers today are at least better than that 10% and are getting better with each passing year. From this grateful thirteen year out heart transplant correspondent, let me say on behalf of recipients everywhere who still wrestle with the issues above, our love and thanks go out to donors everywhere, if not in letters still locked in our hearts, at least in daily thought and prayers for you and your loved one.

And one last thought, as eight year out heart patient Gene acknowledges, “…I know each of the above feelings are just excuses and I hope to someday to be able to write a letter”

For an expanded discussion on this topic, you can read the on-line chapter on patients communicating with donor families at [http://www.rjwitte.com/changeofheart/GiftFromTheHeart/Section2/CHP-31-DONOR-COMMUNICATIONS.pdf](http://www.rjwitte.com/changeofheart/GiftFromTheHeart/Section2/CHP-31-DONOR-COMMUNICATIONS.pdf)