

# Reflections of a Caregiver

*Former Probe staff member Rick Rood lovingly cared for his wife Polly through their twenty-year battle with the degenerative ravages of Huntington's Disease. He wrote this intensely personal and insightful essay a couple of months after Polly's death in the fall of 2003. We gratefully provide his reflections on that journey.*

During these first few months of adjusting to being alone without my dear wife Polly, I've had occasion to reflect quite a bit not only on our nearly 32 years of marriage, but particularly on these past twenty years of walking with her through her journey with Huntington's Disease (HD). And particularly how they impacted me personally. I admit that this is going to be a very personal essay. And parts of it may be tedious at best. But I feel that at the end of this twenty year journey, this is an appropriate time for me to share some of my thoughts, and to fill in some of the gaps in Polly's story. My purpose is not only to share some of my heart, but also to provide a glimpse at some of the ways in which the Lord was at work through this experience, at least to my perception.

Polly and I met during our college years at Seattle Pacific University, and got to know each other well during the year that we both served in student government. I remember to this day being "captured" by Polly's disarming warmth and cheerfulness, as well as by her servant heart. Polly used to spend her summers working at Christian camps. And the summer before we served in student government together, she served as a summer missionary among the Indians of British Columbia. Polly was an elementary education major, and also was a very good pianist. When she was younger she had also been a cheerleader, and was a member of her school's swim team.

When we married on Sept. 11, 1971, we had no idea that

thirteen years later, almost to the day, our lives would be impacted in the way they were when she was diagnosed with HD. There was no clinical test for HD back then. No way to know that you carried this illness, until the symptoms began to reveal themselves. But over the course of a year, and two visits to the University of Texas Health Science Center in Dallas, Polly's doctor concluded that he was "99% certain" that she had this illness. From that moment on, no aspect of our life would be untouched by this reality—physical, emotional, relational, social, vocational, and spiritual. We also knew that her health would gradually decline over the course of the next fifteen years or so, and that only a very small percentage of HD patients survive more than twenty years after onset.

I could detail every step of Polly's journey with HD (and later also with cancer), and fill several pages. But that's not my purpose in this essay. I will only say that her limitations affected every aspect of her person, and that they proceeded slowly and gradually over the course of the next nineteen years, until she was taken home to heaven on August 6 of this year. There were, however, certain "milestones" along the way which I will share with you. The most notable of these was when it became obvious to us that it was time for her to take up residence in a nursing home in August of 1992. Polly never held back from the challenges she was confronted with by this illness. She continued to do all she possibly could. But she gradually had to give up one activity after another: driving, cooking, dressing and feeding herself, etc., etc.

The year prior to her entering the nursing home, I was able to work almost entirely at home for the ministry I served with at the time (International Students). It was unsafe to leave Polly alone, since she easily lost her balance. And she needed someone to feed her at mealtimes, and help her with the other aspects of her life. We had discussed nursing home residency in the past, though it was not something either of us was

entirely comfortable with. But I well remember the day when she sat in our living room and said to me, "Rick, I think it's time for me to move to a nursing home." I think we both knew it was time. Polly needed someone with her at all hours of the day and night. Yet we also had two children to continue raising (Jeff and Jill were 12 and 15 at the time), and a full-time ministry to pursue.

The day I helped Polly move into her room at the nursing home, I stayed with her over the lunch hour. I had never spent much time in nursing homes before. And looking around the room, I realized that we were entering a very different world. Most of the people in this nursing home were quite disabled. It was a culture shock! But with my nightly visits, and development of relationships with the staff and the other residents, Polly's nursing home soon became my home as well. Her world became my world. The highlight of my day for the next eleven years was to drive to her nursing home to be with her in the evening, and when I could to go at lunchtime to feed her her meal! At first, Polly used a walker, and we would walk down to the dining room to sit alone at a table, and talk about our day. She always wanted me to get a Dr Pepper or iced tea, and lift it to her mouth so she could drink it by straw. She loved for me to read to her from various books, and especially from the Bible. I think we read through most of the Bible together—some books several times. She loved Genesis, Isaiah, the Psalms, and the Gospels. Soon Polly was in a wheelchair, and I used to wheel her outside to a bench that was shaded by trees. We would sit and watch the birds, and pray together. A statement Polly made to me a few days after she entered the nursing home reveals something of what kind of person Polly was. She said to me, "Rick, do you think I should start witnessing to the people here?" I've encountered people through the years whose zeal for witnessing probably had the opposite effect they desired. But Polly was not one of them. Just her quiet perseverance and cheerful manner spoke volumes to me, as I believe it did to many others around her. The social worker at

the nursing home where she spent her first four years made these comments about her: "Polly was a very cheerful person. Whenever you would see her she had a smile on her face that could cheer up the world. She was always complimenting others for things they do. She loved a challenge. She played a major part on our balloon volleyball team. Although her health condition limited her in doing some things by herself, she did as much as she could by herself, trying so hard to be independent as much as she could. I remember her face when she used to tell me that she was going out on pass to go to a ballgame, she was so excited. Polly was a very kind and sweet individual who loved her family and she will be missed."

Many fun activities were provided by the nursing home staff, including "balloon volleyball" (which Polly seemed to enjoy a lot), special holiday dinners (she would dress up in her finest dress, and accompany me down the hall to the dining room), outings to various events in the city (e.g. to concerts, the state fair). Actually, Polly's move to the nursing home enhanced our life in many ways. For the year prior to her taking up residence, almost all our time was devoted to "keeping our head above water" (which we didn't always manage to do). We were beginning to sink under the load of all the activities necessary just to maintain our life. But with all the assistance of the nursing home staff to cover many of these things, the time we spent together could now be devoted to other things that added to Polly's quality of life.

For several years I always brought Polly home on the weekends, and always scheduled a special outing or two—to a ballgame, a concert, a movie, a drive to a lake, etc., etc. I found that the anticipation of these events brought an element of hope and joy to Polly during the long weeks at the nursing home. We all need hope—even the little hopes of a change of pace each weekend. I well remember one day probably 8 or 9 years ago now when Polly looked at me and said in her then slurred speech, "Rick, you help make my life worthwhile." My reporting that to

you sounds self-serving, and maybe it is. But I will tell you that that one statement stayed in my heart for many years! On another occasion I recall asking Polly how she kept going in spite of the at times overwhelming difficulties. She simply said to me, "I have the Lord. And I have my family."

About six years ago it became very difficult for Polly to continue eating, and she decided to permit her physician to insert a feeding tube in her stomach. For a while I continued bringing Polly home on the weekends. But with the tube feedings every four hours, neither of us got much sleep, and by Sunday night we were both exhausted. But even after we discontinued her coming home for these extended stays, we still went out Friday evenings (mostly to high school ballgames) and Saturday afternoons, and even to church Sunday mornings (where we sat at the back of the sanctuary). These outings brought me great joy. And it was so satisfying to see Polly smiling, even though she could barely speak anymore.

Polly's physical condition was declining pretty rapidly now. And it was getting much more difficult to transport her places. I well remember one day I think nearly four years ago, when I realized that this particular Saturday was the last time I would likely ever be able to take her out. It was. From that day on, Polly rarely was removed from her bed, except when we transported her to the shower room. Henceforth, it became a matter no longer of bringing Polly to places she could enjoy, but of bringing joy to Polly in her room. While we continued many of our daily routines, it seemed to me that worship became more and more our most meaningful activity. Polly couldn't speak at all anymore, and I am not much of a musician. But I could tell that the worship music that we frequently listened to brought a great deal of comfort to her . . . and to me too. In fact, the past few years it was worship that brought most comfort and joy to my own heart as Polly's caregiver and husband . . . to the very last day of her life. Just before she left us, I was preparing to play

some music. We never got to it. But I'm convinced that she was welcomed into heaven by far more beautiful music and meaningful worship than anything I could provide for her!

As I have reflected more and more on these past twenty years, I've asked many questions. It was only natural, especially at first, to ask "Why?" But we knew that we live in a fallen world, and none of us can claim immunity from life's struggles and even tragedies. It never really entered my mind to ask "What?" That is, "What shall I do as Polly's husband?" I knew that I was with her for the "long haul." No matter what. But I did at times ask "How?" "How are we going to do this?" How am I going to care for her, raise our two children, continue in full-time ministry, and for a few years during this journey also help care for my mother with Alzheimer's, and my dad when he was so seriously ill as a result of working so hard at caring for her. It didn't take me long to realize that apart from the Lord there was no way to do this. It was an impossible task. But I also knew that we weren't "apart from the Lord." He had shown himself faithful to us in so many ways through the years. He couldn't stop now.

Shortly after Polly was diagnosed with HD in 1984, I was reading through the Psalms, and I came to this statement: "Cast your burden upon the Lord and he will sustain you; He will never allow the righteous to be shaken (lit. 'totter')" (Ps. 55:22). In the margin I read that the word "burden" could be rendered "what He has given you." At that moment, the Lord impressed on me that the burden we had been handed was also in some mysterious way I could not yet understand, a "gift" from the Lord. Not something He had caused. But something that He could touch and transform. It would be many years before I would even begin to see how this could possibly be true. As I progressed through my reading of the Psalms, I also came to this statement: "Blessed be the Lord, who *daily* bears our burden" (Ps. 68:19). I knew that if we were going to finish this race, it would be by doing what these two verses urged us

to do . . . and to do it one day at a time. I had for some time kept a journal in which I recorded evidences of God's hand on our life. And over the next twenty years I returned to this discipline many times. Today, this journal is one of my most precious possessions, because it is full of the record of God's faithfulness to us, even though at times my own personal faith was very much of the "mustard seed" variety, if even that! I was also very aware that we needed the prayer support of many other people. And I cannot tell you the encouragement it was for both of us to hear from so many friends across the country that they were praying for us even daily. When I encounter people in the hospital who are under a burden too heavy for them to bear, I always encourage them to enlist the daily prayer support of as many friends as possible. And to ask them to keep praying until they go to heaven!

As I read through this journal, I find evidence of the Lord's activity in our lives in two primary ways. First, in the many things that He did *for* us. I'm sure that there were innumerable ways in which He was working in our behalf, of which we were totally unaware. But I will mention a few of the ways of which I *was* aware. For one, it became evident to me as the years went by that God had been *preparing* us for this long chapter of our lives—primarily by providing models for us. I think for instance of my own paternal grandparents. Among my earliest memories in life are those of watching my grandmother care for my grandfather during the years following his major stroke, in the early 1950s. Then there was the model He provided for us of Bill and Dorothea Hart, who were members of our church in the Seattle area in the late 1970s. Bill suffered from Parkinson's for many years. And he and his dear, caring wife were regular attendees at the church I pastored for five years. What a sterling example they were to us. There was the model of Polly's mother Elsie, who tirelessly cared for Polly's brother Chris for so many years. There was my own father who was so dedicated in caring for my mom during all her years with Alzheimer's. There was the couple we met in

Hayward, CA in 1987, Sherwood and Harvette Peters. Harvette had M.S., and relied on Sherwood's loving care for many years before her homegoing. There were our neighbors, Al and Jeane Olson, who lived directly across the street from us. (Little did we know what a blessing they would be to us when we bought our home, not even knowing they lived there!) Al suffered from a neurological disorder for many years, and his wife Jeane provided such a wonderful model by patiently caring for him. I could mention others, such as Greg and Lisa Hatteberg at Dallas Seminary, who are still contending with Lisa's M.S. And so many others whom God brought across our path to serve as models and examples, particularly for me.

In addition to preparing us, it was also evident that the Lord was *guiding* us and *providing* for us. God's guidance and provision was evident first of all in his enabling me to remain in full-time ministry through these past twenty years, but in ways that allowed me the flexibility to provide the increasing level of care that Polly needed. I frankly did not know how this could be. But how grateful I am for the years I was allowed to serve at Dallas Seminary, International Students, Probe Ministries, and since 1996 in hospital chaplaincy. And for the many, many faithful friends who have supported us in these efforts!

I think of the special families who lived near us, and who helped us shepherd our dear children during the years they were growing up, and we were being stretched beyond our capacities.

The Lord's guidance and provision was also evident at points along the way when we had to make important decisions. I think for instance of when it came time for Polly to enter the nursing home. It was our neighbor Melanie Miller, a nurse, who informed us of Brentwood Place—the one facility in Dallas County that had a preponderance of younger residents (Polly was only 41); and then four years later when Polly's needs were increasing, she informed us of the opening of a new



nursing home on the shores of Lake Ray Hubbard (Sr. Care) where Polly resided for over seven years. I remember also when Polly and I were discussing this decision, being captivated by a story on the evening news that very week about a couple's going through the process of making the same decision we were.

When she first entered the nursing home, we had to jump through a number of legal and financial hoops, including applying for Medicaid assistance for Polly. This was the only way we could afford this level of care. Only those whose total assets fall under a certain limit are able to qualify for this assistance, which ours did at that time. We later learned, however, that if we had waited one more month to apply, we would have been disqualified, and Polly would not have been able to enter the home for perhaps two more years. This was the Lord's doing, and his timing for her.

At other times of decision it seemed that God brought people across our path who had just the insight or encouragement we needed at that particular time. When Polly had to make a decision about a feeding tube for example (which really is a huge decision), the very day that we were contemplating it I entered a room at the hospital where I serve as chaplain, only to find a HD patient and her husband. She had made the same decision Polly was contemplating. I only encounter HD patients in the hospital about once a year! But I encountered her on the very day I needed some encouragement with regard to Polly's decision.

One of our most constant companions these past twenty years was the temptation to discouragement. I'm convinced that there is a spiritual battle that surrounds issues such as these in our lives. There is an enemy who wants to defeat and destroy us. And I found that one of the ways that the Lord encouraged us (I'm speaking for myself here), was through the many small evidences of his presence in our lives. If you were to read several pages of my journal, you would conclude that I had recorded a number of interesting "coincidences" in our life.

But when you string together so many events like these over the course of not only years but decades, it becomes not “coincidence” but “providence.”

For example, I remember a day in the early 90s when a package containing a book came to my desk at Probe Ministries, where I was serving as Director of Publications. Accompanying this package was a letter from the authors of the book. They were asking if we would consider marketing and distributing this book. This was the only request like this that I remember receiving during the years I worked there. I noticed from the cover that the book was a biography or story. How they happened to send this book to us at Probe (an academic/educational ministry), I still do not know. The authors had no way of knowing me, or anything about our life. But what surprised me when I opened the book was that it was the life story of a couple, the husband being affected by HD! Polly's illness. What are the odds? We eventually met the sweet surviving wife of this man about whom the book was written!

I remember another time not long after Polly entered the nursing home that I brought her one evening to a concert at a large church in Dallas. About 4,000 were in attendance. We were a few minutes later than planned, and the lights were already dimmed. It was packed. But there was one seat at the end of one pew on the ground floor, where Polly could sit next to me in her wheelchair. We took our place. I turned to my right, and found that the person right next to me was the director of nursing from her nursing home! I didn't even know she was a believer, or that she would be there that night. What are the odds? There was also the time when I had just finished reading a portion of a book to Polly at the nursing home, then left to attend a service at a nearby church. The pastor's message was on exactly what I had just read to Polly. What are the odds?

Given any one of these instances, I would not think a great

deal about it. But these kinds of events formed a pattern over the course of many years to the very last day of Polly's life! I recounted in my memorial letter about Polly some of the evidences of God's fingerprints on our life during her final weeks and days. But for those who have not read that account, I repeat some of it here. The morning before Polly entered the hospital for the last time, I was preparing for my day and listening to a Christian radio station in the background. As is my custom, before leaving my room I walked over to my bed to sit down and read the day's selection from the devotional "Daily Bread." As I sat down, I reached over to turn off the radio. But before I did, the last words uttered by the spokesperson on the radio caught my attention. He said, "If you knew that today would be your loved one's last day, what would you say to them?" An interesting thought. Then I opened my devotional, and the reading for the day was entitled "Say It Now!" These words appeared in the article: "Recalling the good qualities of deceased friends or relatives at their funeral is appropriate, but how much better to give sincere praise to them while they are still living. It may be the encouragement they desperately need . . . . Don't put it off. Say it today Tomorrow may be too late!" That night when I went to see Polly, I made a special point to be alone with her and to tell her how much I loved her and thanked God for her, and to thank her for all she had done for us as a family through the years. Polly had been unable to speak at all the past few years. But the look in her sweet brown eyes spoke more than words could tell. Little did I know that this indeed would be her last full day in the nursing home. The next night I would be sitting with her in the emergency room as she entered the hospital for the last time. Two weeks later I was up early on the morning of August 6, preparing my breakfast before returning to the hospital. The same radio station was playing in the background as two weeks before. This time a commentator came on the air and said, "You know, when it comes time to die, the relationships that will support us during our time of need, are the ones we have cultivated and nurtured all our

life. We die the way we lived." Less than two hours later I was standing at Polly's bed as she left this world for heaven.

I share these events with you to simply illustrate how over time I learned to take them as reminders, or "markers" along the way, of God's presence and shepherding care over our life. Even in our most difficult hours. One of the many things that the Lord did for us during Polly's long illness.

But just as important as what the Lord was doing *for* us, if not more so, was what I eventually saw as his work *in* us. At least I knew He was seeking to do this in me. Shortly after Polly died, our daughter Jill said to me (and I quickly corrected her), "Dad, I think the reason God put you with Mom was because He knew you had the qualities that would be needed to care for her." I know my heart better than she does, and I said, "Jill, I think one reason the Lord put us together was because He knew I needed to *acquire* the qualities needed to care for Mom." And it's true. I well remember a day (a moment, really), probably five years after Polly was diagnosed, that it dawned on me what God was doing in my life in this regard. And how much growing I needed to do. I can only speak for myself, but I know that when Polly became ill, God enlisted me in a life shaping process. Part of this process involved his gently and patiently chipping away at qualities that He knew needed to diminish in my life. The other part was gradually instilling in my heart the qualities He wanted me to acquire. And I saw primarily three.

The first of these was a sounder *faith* in the Lord. Not that there wasn't faith in our hearts before. But this assignment required faith at a different level than I know I personally had. I'm not necessarily speaking of faith in God's healing power (though I know it's real). Candidly, there were occasions over the years when well-meaning individuals urged us to have faith that God would heal Polly miraculously. One fellow once told me that if we had real faith we would discontinue all of Polly's medications. I don't need to tell

you that I didn't think about this suggestion very long. The kind of faith I sensed God was aiming at growing in us was a trust in his goodness, and the goodness of his purposes, even when it was unknown to us what they really were. Even though life was getting harder every year. This kind of faith comes only from God.

Over the years the Lord used such things as the reading of scripture, times of prayer, the prayers of others, and the recording of instances like those mentioned above, to nourish our faith in Him. Not that we didn't experience times of doubt or discouragement. We did. One thing I did learn, however, was that the experience of pain and sorrow is not inconsistent with faith in the Lord. Paul's letter to the Philippians is full of exhortations to joy and peace, and contains a wonderful affirmation of our hope that to be with Christ is "better by far." But in the middle of this letter Paul makes the honest confession that if his friend Epaphroditus were to die as a result of his recent illness, he would have experienced "sorrow upon sorrow" (2:27). God's word is so realistic and balanced. That fact helped me endure the stormier seasons (as it does now).

The second quality I sensed God working on, and this is really an outgrowth of the first, was *hope*. I am not by nature a very hopeful person. But I learned to grow in this area. I see hope as simply "faith oriented to the future." (I read this somewhere.) An expectation not just of "good times to come," but that as God's goodness has been revealed in the past, so it will be unveiled in the future—even if it comes through encounter with illness and pain. That what the enemy may intend for evil (and which is evil), God can and ultimately will use for good. Even in the face of death (that alien invader into God's created order), there is the wonderful hope of eternal life in heaven, and the resurrection to come!

The third quality God was working on is the most important. That was *love*. I say "most important" because the New

Testament tells us that if faith doesn't produce love, we are "nothing" (I Cor. 13:2). It is useless and dead. I loved Polly before. But this illness tested our love, and took aim at it. Speaking for myself, God used this illness to transform my love for Polly. I learned just how much I needed to grow in genuine self-giving and self-sacrificing love. Not that I didn't need to take time to care for myself. It is possible to neglect your own legitimate needs as a caregiver. And I see some caregivers in the hospital who do this. I remembered that even the "Good Samaritan" delegated some of his caregiving to others so that he could tend to his other obligations (Luke 10:35). But there is a difference between taking care of our needs, and catering only to our own desires. And this is what the Lord was showing to me.

He was showing me just how many ways there are to spell "love." Dressing, bathing, feeding, carrying, smiling, laughing, crying, reading, singing, just sitting quietly . . . . I learned that in a society that places its highest premium on appearance and ability, it is very easy for people whose illness robs them of these very things to feel not only diminished, but also *devalued*. At times the words and actions of others can reinforce this false belief. I learned that the most significant gift I could give to Polly was to communicate to her by my own words and by my actions that she was the most valuable human being in my life. And she was.

I must not fail to mention at this point that not only did I sense the Lord transforming my love for Polly, but also deepening my love for Him. There were times when I felt confused and upset about what the Lord was allowing to happen in our life. I still feel the pain of some of these memories. But as the years went by, and we experienced more and more of God's shepherding care over our lives (even during the very trying times), my love for Him and sense of indebtedness to Him grew and grew. As a result, I sensed a growing passion in my heart to simply worship Him. Both private and corporate

worship became the focus and highlight of my week. I remember reading as a young boy the verse that says, "We love (Him) because He first loved us" (I Jn. 4:19). It's true. The love I feel for Him and the worship I find flowing from my heart, is simply the natural response to His great love, expressed to us in so many ways. When my heart grows cold, and at times it does, one of the things I've learned to do is to bring to mind the many ways in which God has so graciously loved us these past twenty years. "Faith, hope and love; these three remain. But the *greatest of these is love*" ( I Cor. 13:13).

I will tell you honestly that the greatest blessing of my life was caring for Polly. I miss it deeply. And though I would never want her to go through again what she did these twenty years, . . . if she had to, I would be first in line to go through it with her again.

Several years ago, I was reading through the Gospel of John. When I reached the end of the book my attention was drawn to a statement Jesus made to Peter in which he signified to him "by what kind of death he would *glorify God*" (21:19). I had always thought about "*living* to the glory of God." But I had never thought about our "*dying* to the glory of God." I knew at that point that Polly's remaining years were likely few. And I began praying almost daily that whenever it came time for her to leave us, that her departure would bring glory to Him in some way. That was a hard prayer for me to offer. And I don't feel like I was ready for it to be answered until her very last hospital stay. But now that that day has come and gone, I believe God has answered that prayer. In my mind, He has answered it in part by magnifying through Polly all that He has done *for* us, and all He's doing *in* us. And will continue to do until we see Him in glory. *Soli Deo Gloria.*

See Also:

[Grief and Grace](#) by Rick Rood

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## **“My Friend is HIV+”**

A person I love very much was diagnosed as being HIV positive. He was infected at the age of 16. If he had been diagnosed with cancer or some other disease the first thing people would say or think is “How terrible, I will pray for this person.” or “I’m sorry. ” They would also wonder about the injustice of it. Unfortunately, that is not the reaction a person gets from the church when they let people know they have AIDS. The first thing they want to know is “How did you get it. “

Because of this reaction my friend has been totally turned off to Christianity. No one at are chuch knew about him because he was afraid of what people would say. Only his family knew. One day at church the subject of AIDS came up and quickly his fears were realized. Comments such as it being God’s judgment and people getting what they deserve for making immoral choices. You should have seen his face. He was shattered. So was I.

I know that not all churches are like this but so far I havn’t found one that wasn’t. I try and tell myself that this is not our savior talking. If he were here he would forgive and love the person afflicted with this disease. I try to talk to him about Jesus loving and healing the leper. But faced with what is said in our church its hard for him to remember that.

There are so many people struggling with this terrible disease. People who make the same bad choices lots of teenagers in the church are making, but fortunately they only



got pregnant or got someone pregnant. They were lucky enough not to get AIDS. When someone repents, God casts that sin as far as the east is from the west. Too bad we can't do that. It doesn't matter how you got the disease. That person needs to be shown the love of Christ. Don't wait until it's your loved one. Learn the facts about this disease. CHURCH, I beg of you don't let ignorance stop you from being a witness. We are His hands and feet. Lets use them to show a group of people rejected by the church His love. God has not recected those who have AIDS. He is loving them and He is expecting us to do the same. Please pray about this issue.

I am so very, very sorry to hear about this horrible experience. You are so right about the church's judgmental reaction and how it grieves not only the person who has it, and the people who love him, but the Father's heart.

The reason it's so easy for people to react so strongly is that, unlike cancer or stroke or other life-stealing disease, HIV is usually contracted through an immoral lifestyle choice, either sex or drugs. But, of course, as the disease has spread, innocent people get it from those who weren't innocent, and the accompanying unfair judgment just adds to the pain.

You're right, too, all churches aren't like this, but it's hard to find a grace-based church that knows the truth about how God accepts us no matter what. Our church, for example, embraced a man who eventually died of AIDS, and he was greatly loved. But part of that process was educating them about their own risk to exposure to him, and assuring them that unless they came in contact with his body fluids they had nothing to worry about. Which is why some of us particularly delighted in hugging him and kissing him on the forehead to communicate that we cared.

Let me share something someone e-mailed me. I love this story and I bet you will too.

**Slandering The Blood of Jesus** One night in a church service a young woman felt the tug of God at her heart. She responded to God's call and accepted Jesus as her Lord and Savior. The young woman had a very rough past, involving alcohol, drugs, and prostitution. But, the change in her was evident. As time went on she became a faithful member of the church. She eventually became involved in the ministry, teaching young children. It was not very long until this faithful young woman had caught the eye and heart of the pastor's son. Their relationship grew and they began to make wedding plans. This is when the problems began. You see, about one half of the church did not think that a woman with a past such as hers was suitable for a pastor's son. The church members began to argue and fight about the matter. So they decided to have a meeting. As the people made their arguments and tensions increased, the meeting was getting completely out of hand. The young woman became very upset about all the things being brought up about her past. As she began to cry the pastor's son stood to speak. He could not bear the pain it was causing his wife to be. He began to speak and his statement was this: " My fiance's past is not what is on trial here. What you are questioning is the ability of the blood of Jesus to wash away sin. Today you have put the blood of Jesus on trial. So, does it wash away sin or not?" The whole church began to weep as they realized that they had been slandering the blood of the Lord Jesus Christ. Too often, even as Christians, we bring up the past and use it as a weapon against our brothers and sisters. Forgiveness is a very foundational part of the Gospel of the Lord Jesus Christ. If the blood of Jesus does not cleanse the other person completely then it cannot cleanse us completely. If that is the case, then we are all in a lot of trouble. What can wash away my sins, nothing but the blood of Jesus.... end of case!!! God Forgives.. So should we.

Bless you, \_\_\_\_\_.

Sue Bohlin

Probe Ministries

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# Human Genome Project

## What's All the Fuss About the Human Genome Project?

In February of 2001, virtually every media outlet, whether TV news, newspapers, radio, Internet news services, or news magazines, was all worked up about the announcement of the completion of the Human Genome Project. In this article we will explore this monumental achievement and what it means for the future of medicine and our understanding of ourselves.

To appreciate this important accomplishment, we need to review a little basic genetics. It may actually astonish most adults just how much genetics the National Institutes of Health assumes we know about our genetic heritage. The educational video from the HGP includes a three-minute review of basic genetic processes like DNA packaging, transcription of DNA into message RNA, and the translation of message RNA into protein. It's no exaggeration to say that when I played this short piece during a lecture for high school students and their parents, mom and dad were left in the dust.

Honestly, I did that intentionally; because we are only in the beginning stages of a genetic revolution that will transform the way we diagnose and treat disease and how we may even alter our genetic structure. These new technologies bring with them numerous ethical and moral dilemmas we have only begun to address and for which there may not be simple answers. If we

don't take the time to familiarize ourselves with genetic research and its implications, we risk responding out of fear and ignorance and potentially throwing away crucial medical advances.

I have contended for a long time that we can no longer afford to remain ignorant of genetic technologies. They simply harbor far too great a power for both tremendous good and tremendous evil. We must work hard to take every thought captive to Christ and see what there is of benefit and what avenues of research and application we need to avoid to preserve human freedom and dignity.

Well let's talk about our genome, the sum total of all our genes. In most of the 100 trillion cells of our body are 46 chromosomes. These chromosomes are tightly coiled and packed strings of a remarkable molecule called DNA (Deoxyribonucleic Acid). DNA is a polymer, a repetitive sequence of four molecules, which I will only refer to by their one-letter abbreviations, A, G, C, and T. The human genome sequence is simply the sequence of these four molecules in DNA from all our chromosomes. If you laid out the DNA from all our chromosomes in each of our cells end to end, it would stretch six feet long.

A gene is a segment of DNA that contains the precise coding sequence for a protein. And proteins do all the real work in our cells. By looking at our completed sequence, it is predicted that our genome consists of 30,000 to 45,000 genes in each of our cells. So, now that we have the sequence, what does it mean? We'll begin answering that question in the next section.

## **What Does the Human Genome Project Hope to Accomplish?**

The National Institutes of Health in cooperation with several international research organizations began the HGP in 1990 in

the U.S. There were four primary objectives among the many goals of the HGP<sup>[1]</sup>.

The first and primary goal of the HGP was to map and sequence the entire human genome. There is a critical and significant difference between a map and the sequence. There are over three billion letters, or base pairs, in the human genome, spread out over 23 pairs of chromosomes. Trying to locate a sequence of say 1,000 letters, the code for a large protein, is a one in a million task. Therefore, researchers needed a refined roadmap to the genome. The map entails particular sequences that can be used like signs on a road map. If the trait a scientist is studying always seems to be present with this marker, the gene involved is probably nearby. In 1995, a detailed map was published with over 15,000 markers, one for every 200,000 base pairs. This will aid greatly in associating genes with particular diseases. And now with the sequence nearly complete, with over 99% accuracy, determining the precise effect of this gene on disease will be even easier.

A second critical goal was to map and sequence the genomes of several important model organisms: specifically, the bacterium *E. coli*, yeast, the roundworm, fruit fly, and mouse. This information is helpful, because each of these organisms have been used for laboratory studies for decades. Being able to coordinate knowledge of their genomes with cellular and biological processes will certainly inform our study of the human genome and its various functions.

The third important objective of the HGP was to systemize and distribute the information it gathered. Any sequence over 2,000 base pairs is released within 24 hours. The sequence and map data is contained in publicly accessible databases on the Internet. The HGP has also been creating software and other tools for large-scale DNA analysis.

The fourth and final primary goal of the HGP was to study the ethical, legal, and social implications of genetic research. A

full 5% of all funds appropriated for the HGP have been earmarked for these kinds of considerations. There are many concerns revolving around the use of genetic sequence data. Not the least of which are worries about ownership, patenting, access to personal sequence data by insurance companies, potential for job discrimination based on personal sequence data, and the prospects for genetic screening, therapy, and engineering. In the next section we'll begin investigating how the HGP thinks this information can be used.

## What are the Long Term Hopes for the HGP?

The completion of the sequence was announced jointly in February 2001 in the journals *Nature*[\[2\]](#) and *Science*[\[3\]](#). Both *Science* and *Nature* have made these landmark issues available, without subscription, on their websites.

The importance of recognizing the sequence of a particular gene has three important ramifications.[\[4\]](#) The first is diagnosis. Over the last few years, single genes have been found leading to deafness and epilepsy. Numerous genes, however, will influence most diseases in complex ways. Recently, genetic influences have been found in many forms of hypertension, diabetes, obesity, heart disease, and arteriosclerosis[\[5\]](#). Genetic analysis of cancer tumors may someday help determine the most effective drug therapy with the fewest side effects. Genetic diagnosis has the potential to more precisely prescribe treatments for many medical conditions.

Second, diagnosing ailments with more precision with genetics will also lead to more reliable predictions about the course of a disease. Genetic information about an individual's cholesterol chemistry will aid in predicting the course of potential heart disease. Obtaining a genetic fingerprint of a cancerous tumor will provide information concerning its degree of malignancy. Third, more precise genetic information will also lead to the development of better strategies for

prevention of disease.

Many more ailments in newborns can eventually be screened more specifically to avoid disorders later in life. Currently, babies in the U.S. and other countries are routinely screened for PKU, a metabolic disorder that prevents the breakdown of a specific amino acid found in proteins. This condition becomes toxic to the nervous system, but can be prevented and managed with appropriate diet. Without dietary changes, affected babies face extreme mental retardation. Hopefully, the number of conditions this type of screening applies to can be expanded.

Screening can also be done for adults, to see if they may be carriers of potential genetic conditions. Certain Jewish and Canadian populations regularly obtain voluntary screening for Tay-Sachs disease, a known child-killer. This information has been used to help make decisions about future marriage partners.

Perhaps the greatest benefit will come from what is called gene-based therapy. Understanding the molecular workings of genes and the proteins they encode will lead to more precise drug treatments. The more precise the drug treatment, the fewer and milder will be the side effects.

Actual gene therapy, replacing a defective gene with its normal counterpart, is still very experimental. There are still many hurdles to overcome involving how to deliver the gene to the proper cells, controlling where that gene is inserted into a chromosome, and how it is activated.

Not surprisingly, some have seen the human genome sequence as a vindication of Darwin. We'll examine that contention next.

## **Did the Human Genome Sequence Vindicate**

## Darwin?

Amid the controversy and exultation over the release of the near complete human genome sequence has been a not so quiet triumphal howling from evolutionary biologists. The similarity of many genes across boundaries of species, the seemingly messy patchwork nature of the genome, and the presence of numerous apparently useless repetitive and copied sequences all have been laid out for us as clear validations of evolution. Really!

If Darwin were alive today, he would be astounded and humbled by what we now understand about the human genome and the genomes of other organisms.

Let's take a closer look at the claims of one bioethicist, Arthur Caplan<sup>[6]</sup>, who thought the major news story was missed. So let's just pick a few of the more glaring statements to help us understand that little in his comments should be trusted.

First, Caplan says, "Eric Lander of the Whitehead Institute in Cambridge, Mass., said that if you look at our genome it is clear that evolution must make new genes from old parts."

While it may be true that we can see some examples of shared sequences between genes, it is by no means true that we see wholesale evidence of gene duplication throughout the genome. According to one group of researchers,<sup>[7]</sup> less than 4,000 genes share even 30% of their sequences with other genes.

Over 25,000 genes, as much as 62% of the human genes mapped by the Human Genome Project, were unique, i.e., not likely the result of copying.

Second, Caplan says, "The core recipe of humanity carries clumps of genes that show we are descended from bacteria. There is no other way to explain the jerry-rigged nature of the genes that control key aspects of our development."



Not everyone agrees. The complexity of the genome does not mean, necessarily, that it has been jerry-rigged by evolution. There is still so much we do not know. Caplan is speaking more out of ignorance and assumption than data. Listen to this comment from Gene Meyers, one of the principal geneticists from Celera Genomics, from a story in the *San Francisco Chronicle*:

*'What really astounds me is the architecture of life,' he said. 'The system is extremely complex. It's like it was designed.'*

*My ears perked up. 'Designed? Doesn't that imply a designer, an intelligence, something more than the fortuitous bumping together of chemicals in the primordial slime?'*

*Myers thought before he replied. 'There's a huge intelligence there. I don't see that as being unscientific. Others may, but not me.'* {8}

Jerry-rigged? Hardly! Confusing at the moment? Certainly! But more likely to reveal hidden levels of complexity, rather than messy jerry-rigging.

It will take more than bluster to convince me that our genome is solely the result of evolution. The earmarks of design are clear, that is, if you have eyes to see.

## **What are the Challenges of the Human Genome Project?**

In closing, I would like to address what are many people's concerns about the potential for abuse of this information. While there is great potential for numerous positive uses of the human genome, many fear unintended consequences for human freedom and dignity.

Some are justifiably worried about the rush to patent human

genes. The public consortium, through the National Institutes of Health, has made all its information freely available and intends to patent nothing. However, there are several patent requests pending on human genes from the time before the HGP was completed.

It is important to realize that these patents are not necessarily for the genes themselves. What the patent does protect is the holder's right to priority to any products derived from using the sequence in research. With the full sequence fully published, this difficult question becomes even more muddled. No one is anxious for the courts to try its hand at settling the issue. Somehow companies will need some level of protection to provide new therapies based on genetic information without hindering the public confidence and health.

Another concern is the availability of information about individual genetic conditions. There are legitimate worries about employers using genetic information to discriminate over whom they will hire or when current employees will be laid off or forced into retirement. Upwards of 80-90% of Americans believe their genetic information should be private and obtained or accessed only with their permission. The same fears arise as to the legality of insurance companies using private genetic information to assess coverage and rates. A recent bill (June 29,2000) before Congress to address these very concerns was amended to the Health and Human Services appropriations bill, but was removed in committee. The bill will be reintroduced this session.[\[9\]](#) I would be very surprised if some level of privacy protection is not firmly in place by 2002.

Moreover, many are apprehensive about the general speed of discovery and the very real possibilities of genetic engineering creating a new class, the genetically enhanced. Certainly, there is cause for vigilance and a watchful eye. I have said many times that we can no longer afford to be

ignorant of genetic technologies. And while I agree that the pace of progress could afford to slow down a little, let's be careful not to throw the baby out with the bathwater.

After a series of lectures on genetic engineering and human cloning at a Christian high school, one student wrote me to say:

*I am a senior, in an AP Biology class, and I find genetics absolutely fascinating. It's both fascinating and scary at the same time. . . . [You have inspired me] to not be afraid of the world and science in particular, but to take on its challenge and trust God.*

Amen to that!

## Notes

1. "Genetics: The Future of Medicine," *NIH*, Publication No. 00-4873, 2.
2. *Nature*, 409 (15 February, 2001), [www.nature.com](http://www.nature.com).
3. *Science*, 291 (16 February, 2001), [www.sciencemag.org](http://www.sciencemag.org).
4. Genetics: The Future of Medicine, 9-11.
5. Kevin Davies, "After the genome: DNA and human disease," *Cell*, 104 (Feb. 23, 2001), 465-467.
6. [www.probe.org/did-the-human-genome-project-prove-that-darwin-was-right/](http://www.probe.org/did-the-human-genome-project-prove-that-darwin-was-right/).
7. Wen-Siung Li, Zhenglong Gu, Haidong Waing, and Anton Nekrutenko, "Evolutionary analyses of the human genome," *Nature*, 409 (15 Feb 2001):847-849.
8. Tom Abate, "Human Genome Map Has Scientists Talking About the Divine – Surprisingly low number of genes raises big questions," Monday, February 19, 2001, *San Francisco Chronicle*.
9. James M. Jeffords and Tom Daschle, "Political issues in the genomic era," *Science*, 291 (16 February, 2001), 1249-1251.

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