Light at the End of the Tunnel

Reflections from parents whose child with Down syndrome was diagnosed before birth

Although it is very hard,
there is a light at the end of the tunnel.
Allow yourself to grieve for the child
you longed to have,
then allow yourself to learn about
the child to come.
Talk with parents of other children
with Down syndrome
and you'll learn that the differences
are not as great
as you may have thought.
Most of all, love your child –
your dreams for him/her may change
but you can still dream.

Susan – Cranston, Rhode Island

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This booklet has been provided to you by:

National
Down syndrome
Congress

DSAOC
Down Syndrome Association of Orange County

Preface

In isolation, finding out your child has Down syndrome can be a very shocking and scary experience. If this discovery is made before birth, the dilemma can be magnified. Often friends and family cannot relate, and so expectant parents can be overwhelmed with medical concerns, their own fears, as well as the usual new baby issues. Getting understanding, support and up-to-date information from those who have already shared this experience is critical.

From the time the interviews included in this booklet were collected in the late 1990's, medical technology and protocols have developed both in the areas of pre-natal screening and in-utero diagnosis of Down syndrome. The triple screen of alpha-fetoprotein levels (AFP), unconjugated estriol, and human chorionic gonadotropin (hcG) is now commonly combined with checking inhibin (quad test). Moreover, specialized ultrasounds combined with other markers from maternal blood tests continue to be developed to help determine the risk of chromosomal anomaly.

Yet in the crush of statistic-centered and diagnosis-centered information, more than ever it is crucial to connect with person-centered truth about your child's developing life and potential. This booklet provides needed support and person-centered information by addressing specific issues and struggles of expectant parents wishing to prepare for the birth of their baby with Down syndrome. These pages contain excerpts from a survey of parents all of whom have already journeyed down the intense road of pre-natal diagnosis – and chose life. As you read their comments, may their struggles and experiences resonate with your own...generating direction, options and hope.

Linda Chan Rapp, editor
August, 2007

Note: Since 1999, "Light at the End of the Tunnel" has been read by parents from across the United States, Canada and other parts of the world. The first printing was funded by a generous grant from the March of Dimes, Orange County. This reprinting has been jointly funded by the Down Syndrome Association of Orange County and the National Down Syndrome Congress.

Expectant Parents Survey

Question

1

How did you find out that you were carrying a child with Down syndrome during your pregnancy?

I found out that I was carrying a baby with Down syndrome when my triple screen test came back with a 1 in 4 chance of having a baby with Down syndrome. I got an amnio and the test results came back positive. I was four months pregnant. I remember that my doctor was wonderful. I was so very scared, but had 10 days to research before my results came in. I went on the Internet and read every book I could find. I found out that I was afraid of the unknown. Once I read all about Down syndrome, I found out how wonderful my child was going to be and how blessed I was to be chosen to care for this child. My only fear that remained was that my child had a heart defect which required surgery at 5 months. I had a very hard time with that. He has had the surgery and is very healthy. He is now 11 months old and the light of my life.

Denise – Billerica, Massachusetts

While pregnant, I wished I had never had any testing done – that science is a two-edged sword – knowledge and pain. I felt that knowing took away the joy of my pregnancy. And I still feel that if I had to do it over again, I would not have any testing done. It's wonderful to find out that everything is all right, but it's agony having to deal in the abstract – not knowing your child, but knowing there is a disability. The fear is immense. Although I was ready for my daughter's birth and had no sorrow once she arrived, it was a long time coming. It took me four months to accept something that in all likelihood would have taken much less to absorb after she had arrived. Hindsight is wonderful, but doesn't change anything.

Nancy – Cypress, California

What do you remember about the experience?

We found out from the tri-screen (I believe that's what it's called) that our odds for Down syndrome were 1 in 100 or greater. At first, we did not want an amnio, largely because of the risk. But we had a remarkable perinatologist who recommended we do it, and he had come through for us before in our first pregnancy; we trusted him a lot and knew he was not pounding an agenda but really believed in us and understood our ambivalence – and he would be doing the procedure. We actually left the floor, started out of the hospital, turned around and went back, and had it done on the spot. When the results came back positive, we had a terrible day, full of grieving. We were also 7 days away from closing on our first house, our apartment was an uproar, and we didn't know if we could go through with our plans. Eventually friends came to help and shored us up, and we made it. My wife and I undoubtedly remember different things, but I remember being broken-hearted that I thought I would have a child that "didn't look like me" and that I wanted to talk to parents of kids with Down syndrome immediately. That very afternoon, we bundled up our 1-year-old and walked downtown (Manhattan) to the national Down syndrome office [National Down Syndrome Society] and got some literature and some contacts.

Bruce and Elizabeth – Tarrytown, New York

I had an alpha-fetoprotein test that came back abnormal, [with a] 1 in 80 chance of [having] a baby with Down syndrome. I chose to have an amniocentesis done, but it was a difficult choice. We found out at about 20 weeks gestation. I felt I would relax more during the pregnancy and delivery if I knew, one way or the other. Honestly, the original reaction I had was one of complete sadness and overwhelming loss of the "healthy" baby I had planned on. I am so grateful I had some time to prepare, because I was able to educate myself over the next few months. However, there was a point where I had to stop reading, because there are so many health risks we were getting a little anxious. Subsequently, when my son was born, we were prepared to celebrate and love him immediately.

Susan – Midland, Michigan

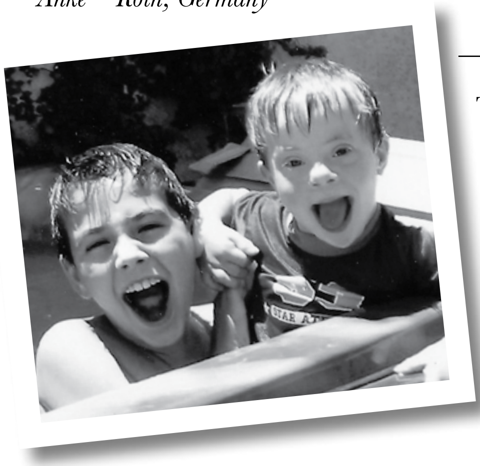
Question 2

Thinking back when you first heard the news of your child's diagnosis, what do you wish you had known then that you know now?

I wish I had known him before!! That question is difficult to answer; we even had read something about Down syndrome in advance because of my age as a mother, but even after that (and it was a new book!) the image of Down syndrome in my head was much worse than reality!

I wish I could send you the feeling of life with my little son with Down syndrome that is so different and so much better than I had feared after the diagnosis.

Anke – Köln, Germany



Loved him in utero.

Kelly – Antioch, California

The biggest thing I wish I knew was what children with Down syndrome were really like. I wish I had made an effort to get to know more families with special needs kids in general, and Down syndrome in particular. I think it would not have been so scary. Of course, this is 20/20 hindsight. I don't know how to tell this to people with a new diagnosis other than to say that the stereotypes are wrong, and before they let their fears get the best of them, they should go and meet real people, and expect to have their socks blessed off.

Ginger – Edgewater, Maryland

Is there anything you wished you had done differently to prepare?

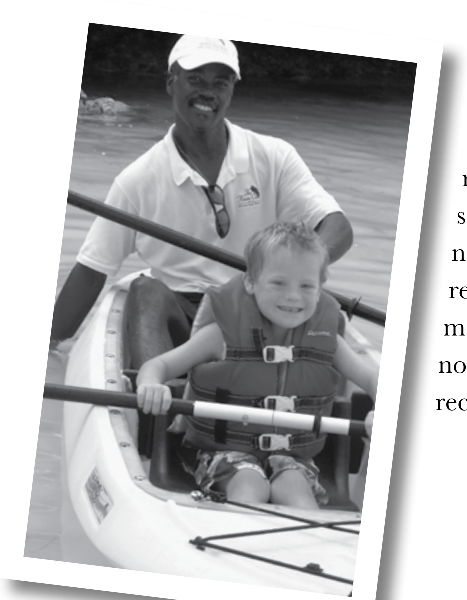
I wish I had known that Down syndrome is a continuum of mental retardation and physical characteristics.

I wish I had known that there were so many professionals to help me with my child – provided by the state (we had financial limitations). Very concerned about the cost of the heart surgery – but the insurance helped, along with MediCal, and so it was not the financial setback I feared.

I wish I had known that so many people would love my son, and so many [folks would be] blessed and encouraged by his presence.

I wish I had realized that it's okay to have weaknesses and a child with weaknesses.

I wish I had known that I would love my child – that I would have a loving relationship as son and mother, not a dependent relationship on me where I got nothing back – but reciprocal.



I wouldn't have done anything differently because I did a lot. I searched the Internet, met specialists, told everyone, and did a lot of research. I did my crying and talked about my fears. I read articles. I was seeking help. At first I felt all alone, but the more information I got, the better it got. And when he was born, it was even better.

Laura –
Arcadia, California

Question 3

What advice would you give to expectant parents who have just learned that their baby has Down syndrome in order to help them

Emotionally – Get in touch with people who know what they're talking about, and steer clear of those who do not. Many more people have opinions about Down syndrome and disabilities generally than actually have experience with them...We can't tell you enough how important it was to find parents. We especially looked for parents in the area to which we were moving, and what an enormous relief to find them, and to find an active support network. I will also tell you what most parents who raise a child with Down syndrome say: this child, like our other, is the love of our life, and we can't imagine life without him.

Logistically – Relax – you're about to have a child with all of the same needs as children without Down syndrome. One of the things we were told was that if we were going to worry about anything, better we should worry about diapers, crib, onesies, clothes, bottles: in other words, the usual stuff. The special needs come along with enough space between them that you have time to deal. We had one child already, and we were told we should prepare just to have a life with two children – a far bigger challenge than having one with special needs!

Medically – Like all medical situations, it's important to find people who are on your side. You'll know them immediately. Parents generally know helpful pediatricians, neonatologists, etc. Don't be afraid to walk away from a doctor if you sense any condescension or inexperience.

Bruce and Elizabeth – Tarrytown, New York

I'm not sure anything prepares you for that kind of news. Really, the biggest thing that comes into play when you hear the news is all the negative stereotypes and assumptions that you have before you really become educated about what Down syndrome means now – early intervention, nutritional therapy, inclusion – these all massively change the picture.

Ginger –
Edgewater, Maryland

in preparing for their child

— emotionally?
— logistically?
— medically?

Emotionally – At 39, and after 17 years of marriage we had wanted a baby for a very long time; then to be told your child would have a disability was disheartening. I tended to withdraw, and luckily for me, my husband's personality sought comfort from friends, relatives, co-workers, neighbors, etc. When people understood how deep our love and commitment was already to this unborn child, everyone was so supportive, helpful, reassuring and accepting (at least outwardly). Our son was to be born at Christmas time so we prepared a "Christmas/Birth" greeting/letter which announced his birth, announced his Down syndrome, and announced our unconditional love for our son. We mailed them out to everyone we knew, even people we wouldn't normally mail a Christmas card to. The response was overwhelming; it cut down on having to explain everything over and over again, especially at the beginning when I was trying to just get used to the idea of being a mom. Another important thing for me was to try to live in the moment and get beyond the fear and the "what ifs." I read a quote when I was pregnant that helped me look at my fears a little differently: "Never fear shadows…they simply mean there is a light shining somewhere nearby" by Ruth E. Renkel. How true that was. The light has been shining ever so brightly since the birth of our son.

Patty – Paso Robles, California

Medically – Have a fetal echocardiogram done, and if a problem exists have it checked every month until delivery. Also, if no problems are found, get another echo in a few months just to be sure they are not missing anything. Jared's VSD (ventricular septal defect) was diagnosed at 20-21 weeks into the pregnancy, and we were able to educate ourselves about the heart prior to birth. It made it easier when he went into the newborn ICU. He is 26 months now and it will be closed soon.

Holly – East Haven, Connecticut

Emotionally – Receiving a diagnosis such as Down syndrome can be overwhelming. Allow yourself to grieve, but realize it soon just becomes a different path that your family will follow.

Logistically – Take the plunge and talk with a parent of a child with Down syndrome. Find someone who can support you with fundamental questions down the road. Call your local Early Intervention person so that your baby can be set up for services (such as therapy or respite care).

Medically – Go ahead and have your child tested for things like heart, eyes, ears, thyroid. Then you can deal with each issue [if] it comes up. If you are not comfortable with a doctor and feel someone else could provide better or more compassionate care, don't hesitate to make a change! In addition, educate yourself on the therapies available.

Susan – Midland, Michigan

Educate yourself as much as you can on Down syndrome. Make sure the material you are reading is current. Things have changed dramatically in recent years with respect to Down syndrome and recommended services. Also, find a Down syndrome support group in your area. It is extremely reassuring to meet other families who have been through all that you are feeling and also to meet other kids with Down syndrome.

Colleen –
Redondo Beach, California

Logistically – Deliver at a hospital with a good NICU [neonatal intensive care unit] in case of complications. That way mom and baby will be close. If I had delivered where I originally planned, I would have been separated from my baby for five days; that would have been awful. Plan to have many appointments, at least for a while. We currently have school (early infant stimulation) once a week and occupational therapy three times a week. We generally have an appointment with one of the doctors about once per week, but that is starting to slow down. Ask for respite from Regional Center [the agency in California that coordinates early intervention/support services]. They don't just offer it, but it is available! And if your child has any special health needs, you'll be assigned a nurse to come to your home and babysit… This isn't for working, but for getting away and/or getting things done, like your own doctor's and dentist appointments, Bible studies, lunch with friends, date night for mom and dad, etc. The idea is to get refreshed so you can be a better parent to your child. …I use mine to do shopping and make all the phone calls that come with having a special needs kid!

Medically – Getting a really good pediatrician who works with kids with Down syndrome who isn't afraid to coordinate all the possible medical needs of our kids is of utmost importance. They need to be aware of the usual problems associated with Down syndrome and not just assume that because a lot of kids with Down syndrome have problems with certain things that it's "okay." Friends of ours had a pediatrician who allowed their baby to not gain weight because of her Down syndrome. That is just NOT acceptable! It may be harder for them to gain weight, but if they don't gain then they need to be put on a special diet. Our kids need doctors who will be aggressive in managing their complications. …For us this has been so important because Megan has a major heart condition and has been in the NICU (newborn ICU), had heart surgery, and been in PICU (pediatric ICU). Not everyone has major problems, but being ready with a great team of doctors is important.

Linda – Chino Hills, California

Question

4

What did you find to be supportive? (Or, what would have been supportive?)

I couldn't talk to others at first; my husband needed to. He felt comforted by getting a ton of information and talking to other parents. I was overwhelmed by the idea. We went online and found that there are some really nutty people out there who think that it's better to have kids with Down syndrome. I felt very angry with them! All I could think was if my baby could be normal that is what I would wish for her! Better than normal is okay, but "below normal"? No way! Well, I've learned that Megan is NOT below normal but you couldn't have convinced me of that before she was born. Even so, as time went on I got more and more used to the idea and I did start to want this baby again… I needed people who could hear how afraid I was, not condone or condemn me, and then still be there the next time I called. I didn't need to be given phone numbers for every support group in the world. We got that on the Internet! I did appreciate being given [names of] personal friends and relatives of my friends who had a child with Down syndrome. I never called them, but knew I could and felt that they may understand a little better. I tried to find someone who knew ahead of time about their child with Down syndrome. I needed to know how to manage normal stuff, like making OB appointments so they were as free of being around a bunch of giddy/happy moms-to-be for a while, that sort of thing. I also needed to just talk to a mom that decided to keep her baby. We did it because we knew it was the right thing to do, not because we were so excited to have a baby with Down syndrome, and I really wanted to talk to someone who could understand that perspective. We never found this, but I was able to be there in that capacity for a woman at our church who found out that her baby had Trisomy 18. I think God used me to help her through her journey, even though the outcomes were quite different…

Linda – Chino Hills, California

I am an action oriented person. I found it helpful to delve into books, Internet, etc. and find out how best to help my child. I found it helpful to act, not sit back in self pity.

Patty – Paso Robles, California

I wish the genetic counselor did not just hand me an appointment time for the termination. Tomorrow at noon. I wish she was supportive and told me the "good" things that could come.

Kelly –Antioch, California

We attended the Connecticut Down Syndrome Congress convention two months prior to Jared's due date; that was probably the best thing we could have done. It was nice to see children with Down syndrome and know that they are really not that different at all. The information we received that day was wonderful; also the contacts and encouragement we received were indescribably valuable.

Holly – East Haven, Connecticut

We immediately went to the Internet and found a strong support group of happy, intelligent, positive parents of kids with Down syndrome (a private news group) – even before our daughter was born. We also connected with other parents with special needs kids – not only Down syndrome, but others. This was probably one of the most healing things we did – by seeing happy special needs families modeled for us, many of the fears that the baby would ruin our family, trash our marriage or take over our lives were put to rest.

Ginger –
Edgewater, Maryland

Question 5

Any additional words of advice or encouragement to expectant parents of a baby with Down syndrome?

Look for the most current facts. Don't plan the future; take a few months at a time. Family will adjust better than you think. I was afraid that my kids might consider [the new baby] a burden. Later I realized that it was up to me not to treat her differently and that they would respond to my actions. My kids adore Mia – I was worried for nothing.

Nancy – Cypress, California

Don't believe your fears. This baby is truly a special blessing and will stretch and enrich your life in ways you can't even begin to imagine right now. This may take a while to come to terms with, however. We all have the "fantasy baby" in our minds while we're expecting. This baby will win every beauty pageant, win the Nobel Prize and cure AIDS, of course. Normally, we are given time to slowly disabuse ourselves of this fantasy as we get to know our children with all their "humanity"– they are wonderful, but different from what we dreamed up in our heads when we were expecting them. News like "Down syndrome" brings the fantasy crashing down around our ears in one fell swoop. You will go through the grieving process of losing the fantasy baby, and you need to allow that to happen. The truth is, however, that the real baby will still be wonderful. Our Carmen is the most joy-gifted human being I know, and she is loved by everyone in our family. Much of the fear is based on untruth. Take time to find out the truth.

Ginger – Edgewater, Maryland

Having a child with Down syndrome has molded me into a better person. It has opened my mind about the incredible frontier our brain is and [I] am learning together with my child. …am also applying principles [that] I am learning to my other son as well. …am very excited about the journey.

Barbara – North Lawrence, Ohio

The single most important factor in whether or not you are going to have a good experience is your ability to have a good attitude about it. That means a good sense of humor, a wide acceptance of difference, and a willingness to learn that some things you used to think are wrong. One of the turning points for us was when we talked to a woman who said that if we chose not to have our…baby, to please deliver it and put it up for adoption, because she helped place babies with Down syndrome for adoption and there was a waiting list of a hundred families! Now we know why. Having Jesse in our family has been an indescribable blessing, not only to us, but to many, many people around us. We're living a whole new life, and we wouldn't trade it for our old life for the world.

Bruce and Elizabeth – Tarrytown, New York

Remember that the child you're expecting is still the same child you conceived. It is only your expectations that get in the way of acceptance. Each child on this planet is unique, including the one you are carrying. Live each day for the glorious day that it is and be thankful for the gift God has given you.

Patty –
Paso Robles, California

It's not the end of the world. In many ways it is more rewarding than having a "regular" baby. You take nothing for granted. I am always amazed at how close to normal my son is progressing, something I otherwise would have taken for granted. Today, Liam found his shadow for the first time. The sunlight was streaming in through the kitchen window and he was crawling on the floor exploring. I looked down and saw something had caught his eye. He was rocking back and forth giggling. I looked down and saw his shadow on the wall. I watched for the next five minutes as he moved his head and arms and watched his shadow move. Would he have found his shadow at this time if he was a "regular" baby? Probably. Would I have noticed at this time and shared his happiness? Probably not. I might have been more concerned with the dust on the baseboard.

Kathy – Belle Harbor, New York

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National Down Syndrome Congress

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The opinions, findings and conclusions or recommendations in this booklet are those of the individuals quoted, and do not necessarily reflect the views of the DSAOC or NDSC organizations, the Children and Families Commission of Orange County, or their membership, if any. All medical and related issues should be thoroughly discussed with your doctor, or your child's doctor, before being implemented.

Special thanks to all the children and families who are pictured in this booklet.

Know that your child
will walk
will talk
will learn
and will grow to be
an important part
of our community.

I can’t stress that enough.

Melinda
Fullerton, California