Our theme for 2004 has really been about building a highway instead of a path. A highway will make the way easier of all of us in the quest to make our vision a reality. Our vision is this: *Children born with chromosome abnormalities will have specific treatments so they can lead healthy and autonomous lives.*

This year we began to build the highway for families and individuals with chromosome abnormalities by bringing together other advocacy organizations and scientific experts to plan our highway building project. We hosted the Inaugural World Congress on Chromosome Abnormalities in June at the Henry B. Gonzalez Convention Center in San Antonio, Texas.

The goals of the World Congress were to:

1. **Build a community of parent-advocates by:**
   - Creating a forum for interaction
   - Disseminating information on a variety of pertinent topics
   - Showcasing success stories
2. **Build stronger lay advocacy groups for chromosome abnormalities by:**
   - Learning about each other’s success
   - Identifying common issues
   - Planning synergistic strategies
3. **Establish the nucleus of a scientific community dedicated to solving the issues faced by people with chromosome abnormalities by:**
   - Developing models for clinical evaluation
   - Identifying universal research themes
   - Establishing “crosstalk” between medical/scientific subspecialties

The other advocacy organizations that served with us as host organization were:

- **Support Organization for Trisomy 18 and 13 (SOFT)**
- **Distal Trisomy 10q Families**

The World Congress drew almost 500 attendees including affected individuals, family members, allied health professionals, physicians and scientific experts. This diverse group discovered that they are each energized by the others, and new collaborations, alliances and friendships were made.

Elsewhere in this publication there is a report about the family conference perspective. There is a list of the scientific leadership and there are pictures of the action.

A program book was published for all the attendees that include the abstracts from the scientific presenters. If you would like a copy of the program book, please contact the office.
Educational Events by Registry Members

One of the major goals of The Chromosome 18 Registry & Research Society is to educate the public concerning the varied syndromes of chromosome 18. Some of our very best educators are our families. During 2004, our parents made it their responsibility to share with others the knowledge they gained by being members of The Chromosome 18 Registry & Research Society. Following is a summary of just some of the educational events that took place in 2004 and who conducted them.

Alper Family of NY:
- In November, was interviewed by the NBC TV affiliate in NYC in regard to the 18q– and the research fundraiser the Alper family was hosting the following week in honor of daughter, Sydney who has 18q–.

Deb Ammann of FL:
- In February, gave family doctor and nurse information on 18q– and how it affects her son, Kevin.
- In August, presented to school personnel what 18q– is and its effects on her child.

Marlene Brightwell of Australia:
- In August, in Perth, a meeting of local families to plan the 2005 Australian conference. Present were two doctors as well as parents of affected chromosome 18 individuals.
- In July, Marlene was a guest speaker at the annual “Genetic Disorders Awareness Week at the Powerhous Museum, with 110 people in attendance.
- In December, attended Family Advocacy meeting on integrating people with disabilities into the community and self-employment for the disabled.
- In December, attended an event for International Day for People with Disabilities.
- In December, had a general meeting and social day in Sydney attended by 17 people.

Liz Grossman of FL:
- Continued development of a support group she founded “A Very Special Mom’s Club, Palm Beach County, FL. Took opportunity to host workshops, presentations and social outings and distribute information concerning the World Congress on Chromosome Abnormalities.

Beatrice Luna of TX:
- Presented to 18 Edinburg LVNs information about chromosome 18 anomalies, especially 18q–, the Chromosome 18 Registry and its resources, and goals for those affected by chromosome 18 anomalies.

Denise Moon of CA:
- In June, presented program in the Transition Parent/Student Program for the Irvine School District and Newport Mesa School District, with emphasis on disabilities associ-
Club members an overview of the work of The Registry, chromosome 18 anomalies (especially Tetrasomy 18p), educational challenges, and the outlook for the future of those with chromosome abnormalities.

Kristi Street of TN:
• In August, met with a resident and an x-ray technician at local hospital. Made presentation on chromosome abnormalities, growth hormone research, thyroid disorders, molecular testing, and red flags for chromosome analysis and signs to consult specialists.

Angie Moss of CO:
• In January, eight regional families gathered to discuss conference activities, treatments that are or are not working for our children, network about doctors and resources available on state and local levels.

Stephanie Roach of UT:
• In June 2004, met with area families to discuss the activities and progress of their children.

Veronica Rowe of Australia:
• Organized and hosted the Annual Family Meeting in Perth, Western Australia, a two day event with social and educational exchange by 38 people from Western Australia, Queensland, Victoria and New South Wales.

Katie Schilly of KS:
• Made a presentation to a local Olathe Mom’s Club about chromosome 18 anomalies, the Registry and its work and goals for the future.

Stephanie Shively of IL:
• In September, presented to a group of 17 Paxton Rotary

Hampton Elementary School in Hampton, especially his progress after growth hormone treatment.

In August, met with a resident and an x-ray technician at local hospital. Made presentation on chromosome abnormalities, growth hormone research, thyroid disorders, molecular testing, and red flags for chromosome analysis and signs to consult specialists.

“When you reach for the stars, you may not quite get them, but you won’t come up with a handful of mud either”

~ Leo Burnett

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### Member Summary

#### Identified Families:

<table>
<thead>
<tr>
<th>Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>18q-</td>
<td>484</td>
</tr>
<tr>
<td>18q– mosaic</td>
<td>24</td>
</tr>
<tr>
<td>18q– interstitial</td>
<td>19</td>
</tr>
<tr>
<td>18p–</td>
<td>251</td>
</tr>
<tr>
<td>Ring 18</td>
<td>120</td>
</tr>
<tr>
<td>Ring 18 mosaic</td>
<td>8</td>
</tr>
<tr>
<td>Tetrasomy 18p (includes partial)</td>
<td>124</td>
</tr>
<tr>
<td>Tetrasomy 18p mosaic</td>
<td>7</td>
</tr>
<tr>
<td>Trisomy 18</td>
<td>388</td>
</tr>
<tr>
<td>Trisomy 18 (mosaic)</td>
<td>23</td>
</tr>
<tr>
<td>Trisomy 18q (includes mosaic)</td>
<td>29</td>
</tr>
<tr>
<td>Trisomy 18p (includes mosaic)</td>
<td>12</td>
</tr>
<tr>
<td>Other</td>
<td>204</td>
</tr>
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</table>

#### Our identified families live in:

<table>
<thead>
<tr>
<th>Region</th>
<th>Count</th>
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</thead>
<tbody>
<tr>
<td>United States</td>
<td>1312</td>
</tr>
<tr>
<td>Europe</td>
<td>171</td>
</tr>
<tr>
<td>Canada</td>
<td>85</td>
</tr>
<tr>
<td>Australasia</td>
<td>60</td>
</tr>
<tr>
<td>South America</td>
<td>17</td>
</tr>
<tr>
<td>Central America/Caribbean</td>
<td>5</td>
</tr>
<tr>
<td>Africa</td>
<td>8</td>
</tr>
<tr>
<td>Asia</td>
<td>10</td>
</tr>
<tr>
<td>Mexico</td>
<td>6</td>
</tr>
<tr>
<td>Middle East</td>
<td>5</td>
</tr>
<tr>
<td>Oceania</td>
<td>1</td>
</tr>
</tbody>
</table>
The major accomplishment of 2004 was the **World Congress on Chromosome Abnormalities**. The scientific sessions included speakers from around the world. Sessions were presented on a variety of chromosome abnormalities as well as on a variety of topic that are critical to advancing our knowledge of these conditions. The culmination of the World Congress was the creation of meeting of seven working groups. The working groups are:

**Scientific Leadership:**

Co-Chairs:

**Jannine D. Cody, Ph.D.**

(18q-, 18p-, Tetrasomy 18p, Ring 18) University of Texas Health Science Center at San Antonio

**Daniel E. Hale, M.D.**

(18q-, 18p-, Tetrasomy 18p, Ring 18) University of Texas Health Science Center at San Antonio

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We should be taught not to wait for inspiration to start a thing. Action always generates inspiration. Inspiration seldom generates action.

-Frank Tibot
The Syndromes of Chromosome 18

Papers Published


Papers in Press


Mapping structural differences of the corpus callosum in individuals with 18q deletions using targetless regional spatial normalization. Peter Kochunov, Ph.D, Jack Lancaster, PhD, L. Jean Hardies, PhD, Peter M. Thompson RP Woods, Jannine D. Cody, PhD, Daniel E. Hale, MD, A Laird, Peter T. Fox, MD., Human Brain Mapping

Myelination in Children with partial deletions of chromosome 18q. Jack L. Lancaster PhD, Jannine D. Cody, PhD, Trevor Andrews MS, L. Jean Hardies PhD, Daniel E. Hale, MD, Peter T. Fox MD. American Journal of Neuroradiology

Cognitive Ability and Adaptive Behavior Associated with Extent of Deletion in Children with 18q Deletions. Margaret Semrud-Clikeman, PhD, Nora M Thompson, Ph.D, Becky L Schaub, MS, Robin Leach, PhD, Andrea Hester, MA, Daniel E Hale, MD, Jannine D. Cody, PhD. J Int Neuropsych Soc

See our website at: www.pediatrics.uthscsa.edu/chromosome18/
Fundraising Activities

<table>
<thead>
<tr>
<th>Registry-wide Fundraisers</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Registry has, at this point in time, four separate fundraisers each year that are designed to include the entire membership. The rational behind this is that, in order to press forward with research to better the lives of our children, we must have a system in place that will consistently raise the funds to aid in that research. These events are meant to encompass all member families and extended families. Ideally, each and every member family should participate in one or more of these events which are varied enough that members can choose the event that best fits their style. These four events are:</td>
</tr>
<tr>
<td>- Phantom Tea</td>
</tr>
<tr>
<td>- Birdies for Charity</td>
</tr>
<tr>
<td>- San Antonio Golf Tournament &amp; Silent Auction</td>
</tr>
<tr>
<td>- Run for Research</td>
</tr>
</tbody>
</table>

**San Antonio Golf Tournament**

Because the World Congress took place in late June, the annual San Antonio Golf Tournament, which has also been held in June, was not able to be hosted. But Jim and Claudia Traa did not rest. They started planning early for a one-time event called Run for the Chromo, which coincided with the World Congress. See more about this under the World Congress article. This event raised $17,580.00.

Two of the above four events overlap into two separate years. They are the Phantom Tea and the Birdies for Charity. Both start in the fall and carry over into the next calendar year.

**Phantom Tea**

The 2003-2004 Phantom Tea kicked off in October 2003 and extended to July of 2004. The total raised for this event was $138,160.75. Donations were made by 735 people in honor of 61 of our affected children or adults, which represented 14.5% participation of the U.S membership.

**Birdies for Charity**

The Birdies for Charity is an event held in conjunction with the PGA Tour Pro Tournament in San Antonio that raises substantial dollars for charities in the San Antonio area. Preparations begin in July and end with the tournament in October.

2004 was the fifth year that the Registry participated, and it brought in $10,849.08 in pledges, straight donations and contest winnings. It should be pointed out that Golf San Antonio who runs this event does not get the final total and donor list to us until February of the following year, so most of the dollars and donors are actually recorded in following financial year's annual report.

**Run for Research**

Four Registry families took part in the 2004 Run for Research. On October 16th, the Shively family from Buckley, Illinois, hosted their third Run and they (including Aunt Karen Lanning) and their many friends walked, ran, biked, etc. to bring in $26,981.41 in honor of Sara who has Tetrasomy 18p.

In the community of Katy, Texas, the McDivitt family hosted their second Run for Research on April 24th. John and Monica McDivitt, along with their supportive family and friends, walked and ran their way to $8,327.50 in honor of their daughter, Samantha, who has 18q-.

On May 23rd, Mark and Maureen Gullickson of Broken Arrow, Oklahoma, hosted the Run in memory of their son, Caleb, who had Trisomy 18. Their efforts contributed $780.00 toward research.

Pamela Del Angel, who lives in Houston, decided to try doing a Run in the Valley where most of her family lives. Pamela’s unbounded energy and love for her son, Tristan (Ring 18) resulted in an amazing first-time effort of $5,867.00.

**Individual Fundraisers**

In addition to our four Registry-wide fundraising events, individual families are invited to take on the responsibility of creating their own fundraiser. The Chromosome 18 Registry & Research Society has been blessed to have some families who are not only energetic, but very creative. They enlisted the help of their families, friends and communities to raise awareness of chromosome 18 syndromes abnormalities and raise money to fund the research that is changing and improving the lives of their children.

During 2004, there were eleven individual fundraising events hosted by the family and friends of our affected children and adults. We wish to acknowledge those of you who went out of your comfort zone and helped raise research funds your children.

Doug and Julie Masterson (Jake, 18q-) from Pacific Palisades, California, were on the golf course for the 5th time to host what has become a much-anticipated golf tournament/silent auction attended by friends and colleagues. Their hard work always results in a very successful event that continues to be a very important spoke in the fundraising wheel each year. We are so grateful, Doug and Julie, and we thank you for your faithful participation.

Suzanne Passalaqua (18p-) continues to contact her family and friends who know she is coming to their door to tell them about 18p- and ask for their financial support. She is a great example of one of our adults who wants to educate those she knows about her chromosome abnormality. Thanks so much, Suzanne.

Anita Wagner (Kiana, Ring 18) from Las Vegas, Ne-
vada, planned a fundraiser that consisted of a portion of ticket sales for an ice hockey game between the Las Vegas Wranglers and the San Diego Gulls. She used the opportunity to educate the public about Ring 18. Generous friends also made donations. Local media coverage made Kiana a famous little girl!

Thank you, Anita.

Stephen and Ellen Botello from West Barnstable, Massachusetts, (twins Cameron and Joshua, 18q-) continue their amazing success by hosting their fourth golf tournament. While the Masterson family is the anchor on the West Coast, the Botello family holds down the East Coast with their annual golf tournament. We thank you sincerely for all your efforts. Special thanks to Jean D’Olimpio whose skills and hard work help make this event so successful. Thank you, Stephen, Ellen and Jean.

Mike Reilly from Columbia, Missouri, is a friend of Dan and Katie Schilly (Remy, 18q-), and he hosted his fourth golf tournament to benefit The Registry. Here is an example where not just family, but friends of our children, host fundraisers to help in the research efforts. Thank you, Mike Reilly.

Greg Krause, brother of Jill who has 18q- is an dedicated runner. Before a 2004 marathon, Greg collected pledges in honor of Jill, adding the proceeds to research funds. Thanks so much, Greg.

Cheryl Frayne is the aunt of Talia Grossman (18q-). Cheryl and her family live in Canada. After attending the World Congress, she knew that, even though they didn’t live in the U.S., she and her family could do a fundraiser to help in the all-important effort to educate and help research. The family hosted a “Fall Get-Together” and it brought out dozens of interested family and friends. Thank you so much for your help, Cheryl and family.

Bruce Steinke (Dylan has 18q-) faithfully sends us checks several times a year from the proceeds of the vending machines he keeps supplied in his office at The New Republic. Thank you, Bruce and Dina.

Mark and Ruth Getz and their family continued their tradition of having a garage sale, with proceeds and donations being sent to The Registry. Here is an idea for any family who feels they don’t want to host a big event. We all know garage sales are fairly painless and a sure way to raise funds while ridding the house and garage of clutter. Thank you to the Getz family.

Eric and Allison Alper (Sydney, 18q-) of Dix Hills, New York, with the help of many family and friends, hosted their second Comedy Night/Raffle at a local hotel. They again raised tens of thousands of dollars for research. Of course this kind of event does not happen without a great deal of work, but Allison and gang are not afraid of work! Any concerns or worries about whether it would be a success event melted away as the date approached. It was truly another astounding success. Thank you to the entire Alper gang!

Jeanne Koehler of Lansdale, Pennsylvania, collected donations while having family and friends help build gingerbread houses for Christmas. This was in honor of son, Kyle Koehler (18p-/Trisomy 3p.)

Thank you, Jeanne and family!

Other Areas of Giving
In addition to fundraising events, there are numerous other ways that people share with the Registry Family. They include the following:

- Combined Federal Campaign
- Memorials
- Matching Gifts
- Donation with dues payment
- Donors Choice
- Research pledges
- Charitable endowments
- Charitable awards
- Special events (birthdays, anniversaries and special occasions)
- Workplace Giving
- In-kind donations

Memorials
During 2004, contributions were made in memory of the following persons:

Kathy Beninga
Arissa Bianca Chavarria
Sidney Crell
Jenna Crutchfield
Daniel Fleisher
Richard E. Goldberg
Nathan Hicks
De Laney Hunking
David Kayser
Roger Meleen
Nancy Murphy
Mr. & Mrs. Bob Murra
Wesley Oltmanns
Eloise Onan
Ethel T. Smith
Ambrey Speth
Catherine Mary Sullivan
Olli Tontti
Phillip Wendell
Hillary Wexler

Pledges
Several families or family foundations have made pledges to provide financial help for research efforts that are given over a period of years. These pledges continued to be honored during 2004. We are very grateful for their generosity.

Our sincere thanks go out to the generous and thoughtful people who gave in one of these avenues. All donors are acknowledged in the Annual Report except the Combined Federal Campaign. These donors cannot be named unless specific permission is given by them to the Registry office.

Pat Bailey (RemySchilly’s grandmother) in the new Buick Rainier she won by donating to Birdies for Charity.
The Inaugural World Congress on Chromosome Abnormalities
San Antonio, Texas
June 27–30, 2004

Each year The Chromosome 18 Registry & Research Society hosts a family conference. Many people look forward to these meetings in order to meet other families dealing with similar issues and learn more about chromosome 18 syndromes. These educational events give us valuable information about our unique kids. At these meetings we meet new friends, visit with old friends and are fueled with energy and hope.

In June 2004, we stepped outside of our comfort zone and shared our vision. Several years prior to The World Congress, the Board of Directors of the Chromosome 18 Registry realized that groups and individuals with all kinds of chromosome abnormalities needed to come together. After all, we share a sentiment that is actually our mission statement: those born with these chromosome abnormalities will overcome the challenges they face so they may lead more happy, healthy and productive lives. After nearly two years of planning, the Inaugural World Congress on Chromosome Abnormalities came to fruition, and it was hosted in San Antonio, Texas.

Our annual Chromosome 18 conference was set-aside for one year so we could include individuals, families, physicians, scientists and educators interested in any chromosome abnormality. The host organizations were: The Chromosome 18 Registry & Research Society, Disorders of Chromosome 16 (DOC16), Support for Trisomy 13 & 18 and related disorders (SOFT), Chromosome 22 Central, Isodicentric 15 Exchange, Advocacy & Support (IDEAS) and Distal Trisomy 10Q. Many representatives from other groups or syndromes were in attendance as well.

This first-time Congress was literally jump-started with another inaugural event, The Run for the Chrome. On Saturday, June 26, Mark Johnson, with the help of his friends and family, ran 88 miles to benefit The World Congress on Chromosome Abnormalities. Mark’s inspiration was his sister Wendy, who is affected by the chromosome abnormality we know as Down syndrome. It was very motivational for Mark to start this journey from the steps of his sister’s group home in Marble Falls, Texas, and end up on the steps of the Henry B. Gonzales Convention Center, the site of the World Congress on Chromosome Abnormalities just as the meeting convened. A wise man once said, “Obstacles are what you see when you take your eyes off the goal.” Mark’s goal is our goal, to raise awareness for the need to aggressively pursue chromosome research.

Mark Johnson is a Lt. Colonel in the United States Marine Corp. We are so proud that he took some of his free time, when not actively serving his country, to help with our efforts for The World Congress on Chromosome Abnormalities.

During our welcome reception Sunday night, a local musician and piano teacher, Mary Kay Archuletta, had her wonderfully gifted students perform for us. Her students face their own challenges, and some have chromosome abnormalities as well. They delighted the attendees and touched all of our hearts. They were a powerful testament that with love, determination and support, anything is possible.

The Monday, Tuesday and Wednesday meetings were divided into scientific and family sessions, with over sixty
speakers from both the United States and Europe. In order to plan for and manage all of the speakers, attendees and all of the details that accompany an event like this, a planning committee was formed, and they met the task at hand. Countless volunteers helped prior to and during the conference. There was a wide variety of topics for both families and scientific sessions. Some of the family sessions focused on medical needs such as orthopedics, ENT issues, food allergies, mobility choices, neuropsychological testing, speech, visual processing, sensory integration, digestion, neurology, dental issues, ophthalmology, potty training and sleep issues and cardiology concerns. The family sessions included social skills, ADD/ADHD, autism, advocacy, grief and loss, power in medical decision making, behavioral aggression, financial planning, fundraising, starting a lay advocacy group and communication.

Scientific talks involved in depth discussions on specific chromosomes, general genetics including biomolecular and clinical discussion as well as metabolic and endocrine implications. In addition to the high caliber scientific presentations, many of the scientists and researchers convened again on Thursday for a working session to continue the dialogue begun in the sessions and determine a direction and timeline for future projects.

A major highlight of the conference was the panel of several young adults affected by a chromosome abnormality. In a panel setting, they discussed their interests, concerns and talents with the audience and answered questions.

We thank all of those who helped to make the World Congress such a success, especially the planning committee; Jannine Cody, Ph.D., Gloria Ellwanger, Daniel E. Hale, M.D., Trey Homan, Linda Koehler, Carol May, Jennifer Reeves, Rebecca Schaub, M.S., Bridgette Soileau, Rose Tierney-Gumaer, M.S.M., R.N., Claudia Traa, Marsha Zimmerman. There also were over 50 volunteers who also donated their time and talents before, during and after the World Congress. We truly could not have done it without you.

The benefits from this initiative are innumerable. Relationships were made, parent-to-parent, scientist-to-scientist, teacher to child, and doctor to patient. It was just the start of more studies, discussions, advocacy and education. The work of The World Congress was set into motion and will continue. We will once again veer off our familiar path and have our second annual World Congress, though a year has not yet been determined.

The runaway smash hit of the World Congress was the Adult Panel moderated by Dr. John Carey. These ladies told the attendees how it really is. From left to right: Michelle Moon, Suzanne Pasalaqua, Erin Brightwell, Lauren Kato, Jill Krause, Susan Baldwin, Elizabeth Cody and Kathryn McKerracher.
One Family's Story
By Pamela DelAngel

When the Registry asked me to write our story, I was thrilled. I had learned so much by reading about others, I welcomed the opportunity to try and help other families. Surprisingly, writing our story was more difficult than I anticipated. I sat at the computer and thought back to the events of July 2001. It’s amazing how many details I had forgotten about those first few weeks after Tristan was born.

I was working in sales in Tulsa, Oklahoma, focused on taking the corporate world by storm. When I discovered I was pregnant, those aspirations were set aside, and I devoted myself to providing the best possible life for my baby. I enjoyed a comfortable, uncomplicated pregnancy with excellent prenatal care. My doctor ordered the routine blood tests and several ultrasounds, which confirmed my expectations for a healthy baby. The day finally arrived for my baby to enter this world; however, I was completely unprepared when the doctor delivered a stark white baby boy who was not breathing at birth. I remember the complete silence that fell upon the medical staff in the delivery room and the five days of endless tests and diagnosis (and often misdiagnosis) that followed. I am still not sure if it was the shock or the medication, but I remember feeling as if I were in a dream.

When I finally held Tristan, I fell completely and helplessly in love with him. I saw the physical abnormalities, but to me, he was perfect. I was sure the doctors were mistaken and that somehow God was going to fix everything, but after a few days, I could no longer deny the truth. I knew all the tests, pokes to draw blood, and specialists who visited his bedside would not be necessary if Tristan were completely healthy. I hated sitting there, helpless, scared, and frustrated, watching the baby I’d been waiting for my whole life examined like some new scientific discovery. It became clear that my child's future was not going to be thestorybook fantasy I had expected.

The final list of defects revealed by the test results included PDA in his heart, hypospadias, ptosis of the right eye, hearing loss, severe far sightedness, microcephaly, a cleft palate, and dysplasia in his right hip. The NICU doctor informed us that geneticists would need to evaluate my baby boy as was required for any birth with more than three abnormalities.

The fifth day of our hospital stay was the day Tristan was to come home. During the discharge process, we were escorted into a room where we met the solemn faces of the doctors who told us the shattering truth of Tristan’s underlying disorder, chromosome Ring 18. They explained the little they knew of this rare disorder and referred us to information in medical textbooks which included detailed descriptions of the limited life Tristan would experience. Then, perhaps without even realizing the future impact, these doctors offered us the wonderful miracle of hope. They advised me not to believe everything written in those books, and they introduced me to the Chromosome 18 Registry & Research Society web site. I don’t remember much else from the meeting except staring at the table from the web page which stated that 100% of these cases had mental retardation. As frightened as I was by the diagnosis, I was comforted by the knowledge of the Registry. I realized that if an organization existed that researched and supported chromosome 18 issues, then I was not the only Mom who had suffered this news. Through this organization, I learned much information on the disorder. More importantly, I found hope as I read articles from doctors and parents who stated these disorders were not always as debilitating as the medical reports described.

We began therapy with the Early Intervention Program when Tristan was eight days old. At six months, we moved to Houston, Texas, to be closer to family and to afford Tristan the excellent medical care at Texas Medical Center. It was the best decision we ever made. At first, our weeks were filled with so many doctor appointments (endocrinologist, pediatric orthopedics, audiologist, oph-
thallomist, geneticist, cardiologists, urologist, ENT), but we are now down to one or two visits each per year. Tristan has had two surgeries on his hips, another to correct the hypospadias, and then another to insert a set of tubes in his ears. Next year, we face what we hope to be the final surgeries: one to correct the ptosis, and one to remove the pins in his hips.

Tristan also needed up to six therapies per week (including speech, play, occupational and physical therapy) until he was three years old in July. He now receives speech and physical therapy in the PPCD program at our local public school where he attends until noon. After school, he rides the bus to his day care where he has made many friends.

Probably the one thing I dread more than the doctor visits are the scheduled evaluations of his mental capacity. Depending on the person testing and the mood Tristan is in, he typically scores developmentally from 5 to 15 months. However, the tests do not begin to show Tristan’s character and determination to overcome the odds against him. Tristan rolled over at 8 months, and following hip surgery, he crawled at 19 months and walked at 27 months. Although he does not speak yet, we have been trying to introduce him to sign language. We celebrated his success when he signed for “more” pizza!

As I recall all the medical details, one fact becomes clear: that is not our story. Our story is of an amazing blue eyed boy who eradges all the wrong in my world with one high pitched squeal followed by a big smile. A little boy who statistically should not be able to do so many things; yet, he attacks life with a fearless wonder. When we take him to the lake, Tristan will jump off the boat and splash into the water where he floats without a care. He outsmarts his Mom as he wakes up in the middle of the night, turns on the television, and changes the channel until he finds the cartoons he likes. He has learned to walk twice, both times more than a year sooner than his doctors expected. And although his therapist was wonderful, we all know this feat was accomplished because of the persistent determination that drives him to get up each time he falls. People love Tristan, and Tristan loves people. He gives hugs and smiles freely and has no fear of strangers. Our story is of a precious little boy who loves to eat and can instantly point out any song, scene, or character from the Lion King. Tristan attends play groups, goes to the movies and is in day care with all other three year olds. Without signs or speech, he communicates well with adults and other children.

Ring 18 plays a role in our lives, but it is not the lead. Our lives were not always this way, and there are still days when I feel just as sad and scared as I did the day I learned of his chromosome abnormality. However, the majority of the time, I am so busy shuttling him around from horseback riding or Gymboree, trying to instill some discipline (the downside of Tristan’s determination is that he is also extremely stubborn!), and living in the day to day chaos of raising a child, that his disorder is often an afterthought.

There are a few significant events that helped me overcome my initial grief. The first is that I absolutely adore my little boy. He is so happy and loving, that it is impossible to focus on his disorder or pity him. The second is that I have a wonderful support system. Tristan was blessed to be born into a family where grandparents, uncles, aunts, cousins, and friends completely open their hearts to him. He has four cousins within two years of his age, and even in their youth, they love and protect him. It’s heartening to see how they play together as if all is perfect, but at the same time, they make sure he has a toy, cookie, and anything else they may have.

I was also blessed to have a friend in my life that refused to let me dwell on Tristan’s disability. Through his subtle—and not so subtle—pressure, I’ve learned to allow Tristan to take chances and figure things out on his own. And I’ve been amazed at the results. When left on his own, Tristan’s creativity and problem solving skills eventually prevail over whatever sticky situation he manages to get into. And like all three year olds, there are plenty!

The third blessing is my connection to the Registry. At first I was afraid to get involved because that meant admitting Tristan and I belonged to such a group. Then I met the mother of a beautiful little girl with 18q- It was such a relief to speak to someone who truly understood what I was going through. After that experience, I followed her example and hosted a 5K Run for Research in my hometown. We had over 60 runners and raised almost $6,000. It felt great to finally take charge and make a difference in this disorder of which I have no control. That feeling intensified as I watched children as young as two circle the track and say they were “running to make Tristan better” or saw my 80+ year old grandmother circle the track, exhausted but proud as she acknowledged all Tristan goes through on a daily basis. How amazing that one little boy could inspire so many people!

I was also fortunate for the opportunity to volunteer with the World Congress. It was my first conference and a little overwhelming, but I left San Antonio with a sense of peace I hadn’t realized was missing for three years. Seeing how courageous and strong the adults with these disorders were as they spoke of the success in their lives made me proud that Tristan belonged to such a group. I met parents who inspired me to be patient as they told stories of their children finally learning to speak. Meeting so many happy children and their loving parents reminded me that I am not alone in this struggle. The dedication in that Conference Center gave me the conviction to continue to aid the Registry because I know that somehow, we will triumph over these disorders.

I feel as if each day that Tristan grows, laughs, and learns, I chalk up a victory. Like all new moms, I was full of grand ideas for my baby’s future. I had not decided if he would attend Harvard or Yale, but I did know that he would be happy, loved, and make the world a better place. And here we are, only three years later, and he has already accomplished all three. And with the continued support of my family, friends, and the Registry, it looks like I may get my “happily ever after” storybook ending after all.
Programs and Services

Our mission is to help individuals with chromosome 18 abnormalities overcome the obstacles they face so they might lead healthy, happy and productive lives. This mission is accomplished through service, education and research. Our service activities include an annual conference and numerous newsletters. The Chromosome 18 Communiqué is the most widely circulated of our newsletters. Memos for Members is a member’s only newsletter containing information about upcoming events and ongoing projects. Our syndrome coordinators (one for each of the five major syndromes) provide a syndrome-specific closed circulation newsletter for the exchange of information and personal stories among families. Each of our ten Regional Coordinators oversee local events such as family get-togethers as well as local public and professional education. Our newly revised web site is our primary means of public outreach.

We have two main avenues for parents/guardians to share information: the Parent Network and listserves, both open to current parental/guardian members. The Parent Network is simply a contact information list. The online listserves (18q-, 18p-, Ring 18 and Tetrasomy 18p) are maintained by parent volunteers. A relative listserve has also been added, and it is moderated by Julia Wentz, grandmother of Bryan Yocum who has 18q-.

We believe there are no incurable conditions, only those that have not yet been understood. Our goal is to make sure that the syndromes of chromosome 18 are understood. This understanding will bring treatments and therapies that will lessen the burden of these syndromes. The path to understanding the chromosome 18 syndromes is paved with research dollars. Clinical research is very costly, which is why we devote so much effort to fundraising. The price may be high, but the potential rewards are even greater. Research will bring us the answers to the many questions we have about our loved ones. It will give us insight and will guide our actions.

Financial Statement
for the year ending December 31, 2004

Revenue and Support
Membership Dues 9,625
Interest Income (15,399)
Conference Income 118,634
Special Events 99,280
Merchandise Sales 508
Fundraising 189,009
Combined Federal Campaign 20,986
Contributions 45,213
TOTAL 467,856

Expenses
Program Services 329,014
Management and General 11,996
Fundraising 1,109
TOTAL 342,119

Net Assets, Beginning of Year 539,772
Net Assets, End of Year 665,509

Prepared by Cavazos and Coleman, P.C.
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I am an 18p Minus Kid
By Kati Kovacs

I am an 18p minus kid. I bet you don’t know what that means. I will explain it to you. We all have 23 chromosomes. Each chromosome has a long arm and a short arm. The long arms are called q’s and the short arms are called p’s. 18p minus means the short arm of your 18th chromosome has a piece missing. I am 4 feet 8 inches tall which is shorter than most kids my age. I have a wonky hip because it likes to turn in only one direction and not the other. That’s why I cannot run as fast as some of you. I think my wonky hip is because of 18p minus.

Because of 18p, I go horseback riding every Saturday. It helps with my hip and my balance, and makes me stronger. I also do brain gym to help me to concentrate. I have a hard time handwriting, so I hope to get better with my computer so I can use it to write stuff. Even though I am different, I still like to do the same things that other kids like to do, such as watching Lord of the Rings, playing, walking and dancing. I really like having friends like you.

I belong to a group called the 18p Chromosome Research Society. They have annual conferences in the United States. They want to do more research about kids with chromosome 18 problems. At these conferences, my mom and dad hang out with other parents and learn more about 18p. I hang out with other kids and also learn more about 18p.

I go to 18p conferences nearly every year. Last year the conference was in San Antonio Texas. This year it is going to be in Denver, Colorado. And the next year it will be in California. I am going to the one in California but I will miss the Colorado one. I have already been to conferences in Niagara Falls and Denver, Colorado and I went to San Antonio twice.

I have a lot of spirit because of 18p. I never give up and I always try my best. Sometimes I get frustrated and lose it, but I can’t help that. I’m proud of myself but not embarrassed. I’m tiny but mighty. Even though I am different, I’m still the same as you.
Mark Johnson and his sister, Wendy at her home in Marble Falls before embarking on his 88 mile run to the San Antonio Convention Center and the opening of the *World Congress on Chromosome Abnormalities*

Mark Johnson nears the finish line as he passes the Alamo on his fundraising *Run for the Chrome*

Everyone dances to the music of Surrey Lane at the World Congress.

Claudia Traa, Shelley Hunt and Jannine Cody were finally roped in at the World Congress.
I would like to become a member!

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Indicate the chromosome 18 abnormality:
- ☐ Trisomy 18
- ☐ 18q-
- ☐ Tetrasomy 18p
- ☐ 18p-
- ☐ Ring 18
- ☐ Other_________

Name of affected person   __________________________
Their date of birth    __________________________

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