



# Annual Report 1999

## FAMILIES GATHER IN WASHINGTON, DC THE 1999 ANNUAL CONFERENCE

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The theme of the 1999 annual conference was "Making Change Happen." Empowerment certainly describes the event chaired by John McGing. Forty families from all over the country converged on Washington, DC. Families, kids and all, spent an afternoon on Capitol Hill, walking the Halls of Congress educating

their representatives about the syndromes of Chromosome 18. Many families were able to meet with their representatives in person. It was an educational and invigorating experience for all who participated.

Besides the Capitol Hill visit, there were many excellent presentations. David Pitonyak was able to spend almost a full day with us. This stimulating presentation was called, "Supporting a Person with Challenging Behaviors and Supporting the People Who Care." David was wildly entertaining and was full of good humored insight about the behavior of individuals with special needs.

The third day of the conference was focused on medical issues. The chromosome 18 research team from the University of Texas Health Science Center in San Antonio updated everyone



Congressman Roger Wicker addresses Registry members during their trip to the Capitol in July.



Jannine and Elizabeth Cody thank Congressman Henry Bonilla for his support of chromosome 18 research.

about medical and scientific progress. In addition, members were given a lot of background medical information, that will help them understand their child's problems. Dr. Bright, a local orthopedic surgeon provided insight about potential orthopedic problems and how to watch for them. The conference concluded with a relaxing picnic.

The mission of **The Chromosome 18 Registry & Research Society** is to help individuals with chromosome 18 abnormalities overcome the challenges they face so they might lead happy, healthy and productive lives. We do this through service, education and research.



Racine Ghiz entertains the children while they wait in the Capitol to meet Members of Congress .



Bruce Steinke (above) is thanked by Jannine Cody for his continued artistic talent in creating Registry materials. Julie Masterson (below) receives a thank you certificate for the her family's successful golf tournaments.



Conference Chairman, John McGing receives a certificate from Maryland Governor Paris Glendenning. Marie McGing(center) nominated him for his work for the people of Maryland as Chair of our 1999 Registry Conference.

## 1999 HIGHLIGHTS

In 1999 we passed the 1000 family mark. When this organization was formed in 1990, we never dreamt we would be able to touch the lives of so many families.

We had our most successful Phantom Tea fundraiser, bringing in \$81,319.20. The family of Finley Guild generated the greatest number of dollars, as well as the greatest number of donations.

We crossed another hurdle in our quest to get more research interest and funding for the chromosome 18 syndromes. Thanks to the congressional testimony of Jannine Cody before the House Appropriations Sub-

committee on Labor, Health and Human Services, we were able to have language included in the Appropriations Committee Reports from both the House and the Senate which directed the National Institutes of Health to increase and intensify research into the Chromosome 18 abnormalities.

We also sponsored two research projects. One was to develop a new method to perform a fast and more thorough DNA characterization of individuals with any chromosome 18 abnormality. The second project is to begin clinical evaluations of individuals with 18p-

## PROGRAMS AND SERVICES

Members of the Chromosome 18 Registry & Research Society continue to enjoy a host of benefits that improve in quality every year.

The benefits of membership include:

- Publications
- Annual Conference
- Parent Network List
- Regional group membership
- Syndrome group membership
- Web site

We have a wide range of publications, from the widely circulated *Chromosome 18 Communiqué*, to our *Memos for Members* which details organizational news. Each Syndrome Group also

publishes a closed circulation newsletter so that families in each group can communicate informally and semi-privately.

Every year our annual conference provides families with a reason to get to know each other or renew old acquaintances. Oftentimes, families feel like old friends even though they have never met in person because they have communicated using our Parent Network List or one of our email list-serves. The 2000 conference will be in San Antonio, Texas.

Our web site continues to be our best marketing tool. It brings families into our organization from all across the globe.

# FIRST EXECUTIVE DIRECTOR HIRED

In 1999, Claudia Traa was hired as the first Executive Director of The Chromosome 18 Registry and Research Society. Claudia, her husband Jim and two children Ross and Kendal live in San Antonio. Ross is 4 1/2 years old and has 18p- and their daughter Kendall is 3 years old. Claudia has tremendous energy and a passion for our mission that only a parent can have.

Claudia grew up on Long Island and is a graduate of The Catholic University of America in

Washington, DC, with a major in Political Science and concentration in Spanish. She spent a part of her junior year studying at the University of Madrid in Spain. After college she trained as a paralegal. Jim is a graduate of the United States Naval Academy and Claudia worked in several different legal offices as they moved to different duty stations.

In 1997, Jim resigned from the Navy and they chose San Antonio as their home. Currently Jim is the western regional manager of Genzyme Sur-

gical Products.

Ross was born in Pensacola, FL with a heart defect called Tetralogy of Fallot. This finding prompted a chromosome study which determined that Ross has a deletion of chromosome 18p.

Claudia worked as a volunteer in the Registry office and as chairman of the 2000 conference before becoming Executive Director. She is making inroads into the local media community to raise awareness about The Registry and its work.

## FINANCIAL STATEMENT

for the year ending December 31, 1999

### Revenue and Support

Membership Dues	8,225
Interest Income	2,682
Conference Income	13,591
Merchandise Sales	4,185
Fundraising	78,661
Combined Federal Campaign	11,184
Contributions	30,628
<b>TOTAL</b>	<b>149,156</b>

### Expenses

Program Services	79,323
Research Grant	100,000
Management and General	4,066
Fundraising	927
<b>TOTAL</b>	<b>184,316</b>

Net Assets, Beginning of Year	126,523
<b>Net Assets, End of Year</b>	<b>91,361</b>

Prepared by Cavazos and Coleman, P.C.  
Certified Public Accountants

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