



Come with us on a journey.  
We know that our travels will take us far.

FROM HOPELESS...  
TO HOPE.

Because where we have already been  
and what we have already seen  
tells us that

*the potential is endless.*

That, in itself, is reason enough to ask you to come along.  
And help us continue to make the trip  
faster, farther...and possible.



THE CHROMOSOME 18  
REGISTRY & RESEARCH SOCIETY



POTENTIAL HAS LED TO PROGRESS. AND THAT CAN TURN HOPE INTO REALITY.

WE HAVE ALREADY MADE SUBSTANTIAL PROGRESS. WE HAVE MANY CASES THAT ILLUSTRATE THESE CHILDREN HAVE EXTRAORDINARY POTENTIAL. AND WE HAVE MADE DISCOVERIES THAT INDICATE THE UNLIMITED POTENTIAL OF THE RESEARCH, TOO. BUT WE NEED YOUR HELP TO CONTINUE. WE NEED YOU TO SUPPORT AND ENCOURAGE OUR ONGOING JOURNEY TO HOPE. THERE IS AN OLD AFRICAN PROVERB THAT PRETTY MUCH SUMS IT UP.

*IF YOU WANT TO GO FAST, GO ALONE. IF YOU WANT TO GO FAR, GO TOGETHER.*

THIS IS THE TRIP OF A LIFETIME FOR THESE KIDS. THEY ARE GOING PLACES! PLEASE CONSIDER THIS A PERSONAL INVITATION TO COME ALONG.



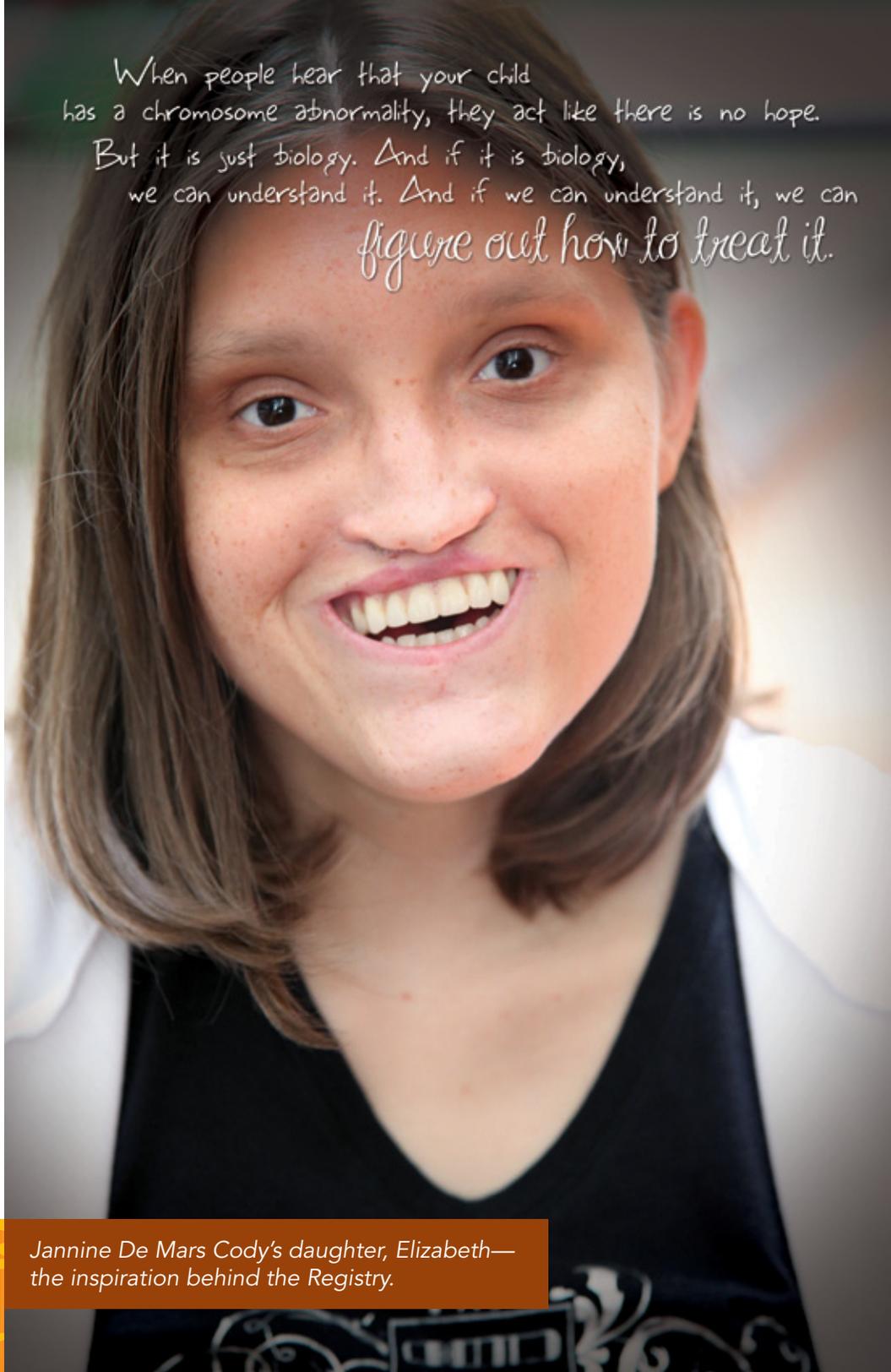
Jannine De Mars Cody: She's the one who began building the road from *Hopeless to Hope*. Why? Because one of her own daughters has a Chromosome 18 condition. Like so many other of the parents in the Chromosome 18 Registry today, she simply refused to accept the diagnosis that her daughter's future was bleak. She looked at her beautiful, lovable, and loving little one—and saw way, way beyond handicaps and disabilities.

SHE SAW POTENTIAL WITH A CAPITAL P.  
SO SHE BEGAN *a journey, a quest.*

She was focused and determined. She did extensive research and sought out experts in everything from growth hormone therapy to neurology to drug behavioral therapy to education. And, with the help of a friend who was a neurologist, she met a group of "moms" who had founded support groups for other medical conditions. She used what she learned from them to set up The Chromosome 18 Registry & Research Society. A non-profit support group of families and friends whose lives have been touched by these children.

The Society's purpose is to find other affected families. Fund research into these disorders. And get the newly-gained knowledge back to the families, doctors, teachers and the public at large.

When people hear that your child has a chromosome abnormality, they act like there is no hope. But it is just biology. And if it is biology, we can understand it. And if we can understand it, we can figure out how to treat it.



Jannine De Mars Cody's daughter, Elizabeth—the inspiration behind the Registry.



Sometimes I had serious medical issues to discuss.  
Sometimes I was just frustrated and alone.  
My CLB family was always there with  
the most incredible amount  
of support.

We want to know why our children have obstacles like learning difficulties compounded by hearing impairments. Speech delay along with poor muscle tone. And a variety of other mental and physical disabilities. Because if we know the why, we can move toward the “how” to continue to help these individuals and many more in the future.

THE DIFFERENCE BETWEEN  
HOPELESS AND HOPE IS *research.*

That’s the job of the research that we’re doing in molecular biology. **New techniques and advances are allowing us to identify and isolate specific genes.** That, in turn, makes it possible to understand complicated conditions like chromosome abnormalities and intellectual disability. **The potential of the research is enormous.** And that’s what drives us forward each and every day—that, and our parents’ determination to improve the lives of their beautiful, precious, extra-special children.



THE DIFFERENCE BETWEEN  
HOPELESS AND HOPE IS ALSO  
*what these children  
can achieve.*

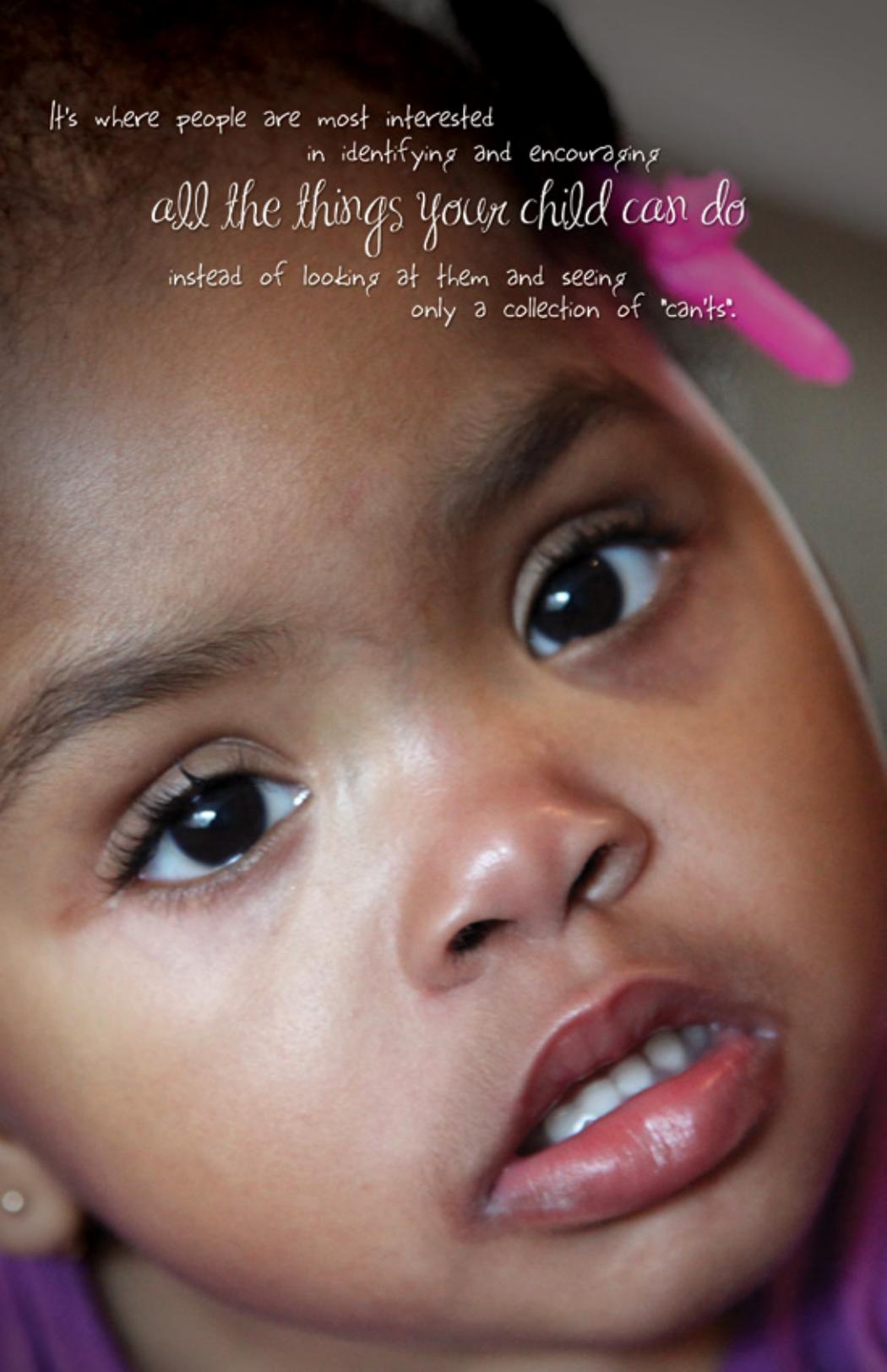
All of our children have complex medical and educational needs. And each child's condition is dependent upon his or her syndrome. Some will, with appropriate therapies and treatment for their medical concerns, be able to live on their own or in a group setting. Others may spend a lifetime gaining basic self-help skills—such as eating without assistance and dressing themselves. However, the majority of children can acquire skills somewhere between these two extremes. That's one of our important jobs at the Registry. **Everything we learn about increasing the quality of life for these children is passed on to the parents, the physicians, and the caregivers. We want each and every one of them to reach their full potential.**

Thanks for seeing our daughter in the way we do...

*beautiful, perfect, amazing*

and just the way she is supposed to be!



A close-up photograph of a young girl's face, looking upwards and to the right. She has dark hair and is wearing a purple top. A pink hairbrush is visible near her hair. The background is dark and out of focus.

It's where people are most interested  
in identifying and encouraging  
*all the things your child can do*  
instead of looking at them and seeing  
only a collection of "can't's".

#### SOME THINGS YOU NEED TO KNOW ABOUT THE CHROMOSOME 18 REGISTRY & RESEARCH SOCIETY:

- We support the Chromosome 18 Clinical Research Center enrollment process. This includes the medical records and DNA banks. Individuals who are enrolled will have the option of participating in studies such as surveys, medical evaluations, and/or treatment trials as such studies are developed and funded.
- We are a non-profit, tax-exempt public charity. We depend on contributions from individuals, businesses, and philanthropic foundations to support our work.
- Our mission is to help individuals with chromosomes 18 abnormalities overcome the challenges they face so that they might lead happy, healthy, and productive lives.

#### SOME THINGS YOU NEED TO KNOW ABOUT THE CHROMOSOME 18 CLINICAL RESEARCH CENTER:

- Our research lab is located at The University of Texas Health Science Center at San Antonio.
- We offer definitive medical and educational resources for the families of individuals with chromosome 18 abnormalities.
- We perform and facilitate groundbreaking clinical and basic research relating to the abnormalities of chromosome 18.
- We provide treatments to help individuals overcome the effects of their chromosome abnormality.
- We have access to investigators from diverse medical subspecialties at the Health Science Center.
- Our Center investigators also collaborate with leading clinicians and experts worldwide.
- No other medical research center in the entire world is doing what we're doing. We are the leader in the field.

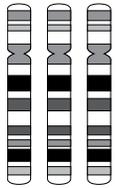


## THE SCIENCE OF CHROMOSOME 18: A BASIC GUIDE

Chromosome 18 is estimated to contain approximately 400 genes. Chromosome abnormalities involve the deletion or duplication of hundreds of genes. However, work with fruit flies and mice suggests that only about 10 percent of these genes function improperly when there is something other than two copies of each gene. The challenge is to find those key genes.

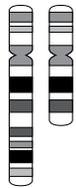
### The most frequent abnormalities of Chromosome 18:

#### Trisomy 18



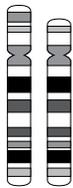
There are three copies instead of the usual two.

#### 18q-



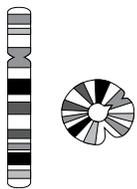
There is a missing piece from the long arm of chromosome 18.

#### 18p-



There is a missing piece from the short arm of chromosome 18.

#### Ring 18



One of the copies of chromosome 18 forms a ring, and material is lost from both the long and short arms.

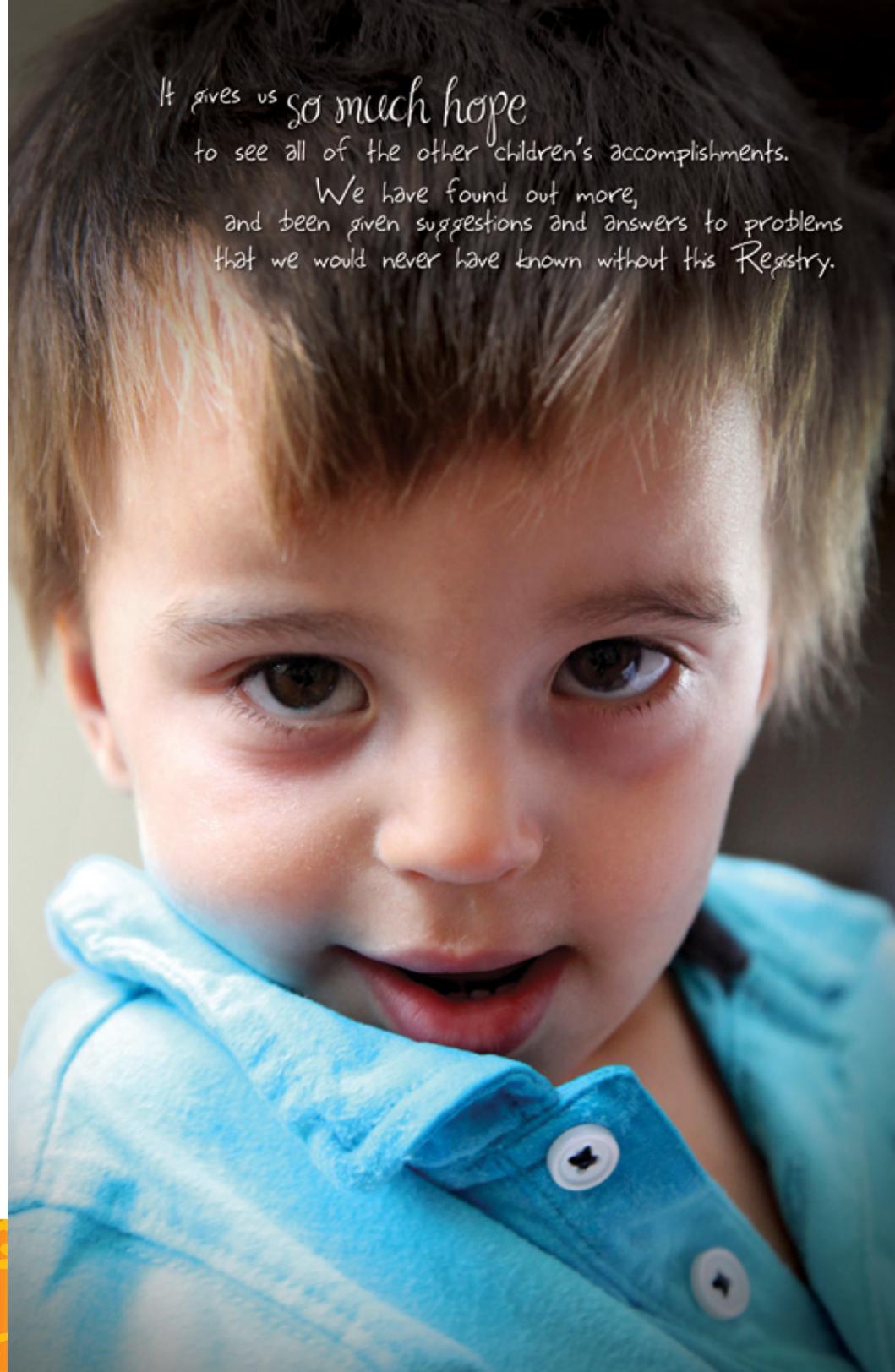
#### Tetrasomy 18p



An extra chromosome is present. This chromosome is made up of two copies of the short arm of chromosome 18.

Note: There are many individuals with other unique arrangements of chromosome 18.

*It gives us so much hope  
to see all of the other children's accomplishments.  
We have found out more,  
and been given suggestions and answers to problems  
that we would never have known without this Registry.*





YOUR DONATION IS NOT ONLY TAX DEDUCTIBLE, IT IS THE BRIDGE BETWEEN HOPELESS AND HOPE.

- Over 96% of the funds donated to us go to our programs; most of that is research.
- We are a non-profit, tax-exempt public charity.
- You can make a contribution by supporting one of our fund-raisers, making a donation online at our website, or by sending your donation directly to:

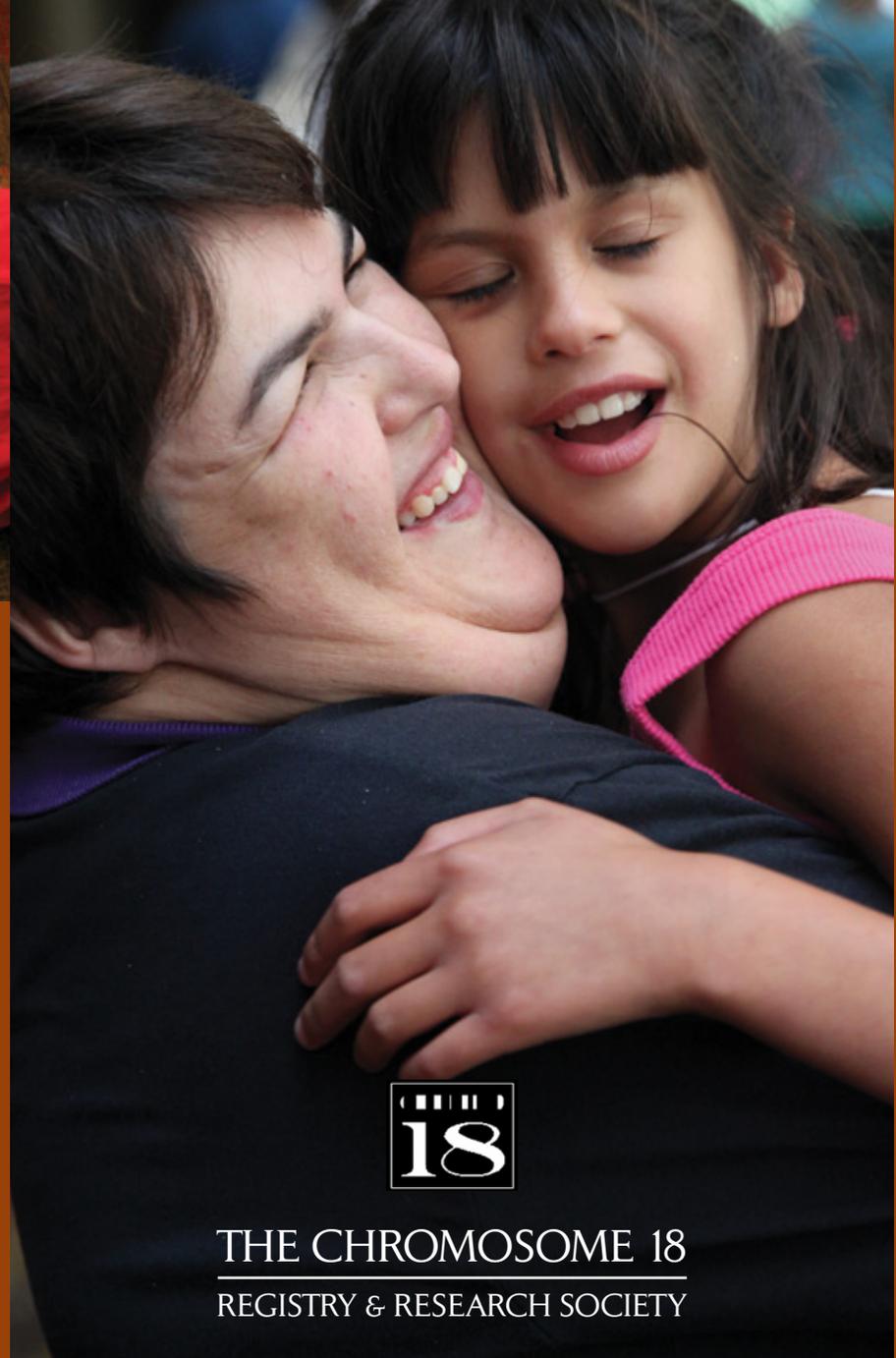
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*Photos by Rick Guidotti, Positive Exposure*



**THE CHROMOSOME 18**  
REGISTRY & RESEARCH SOCIETY

