



CHROMOSOME 18 REGISTRY & RESEARCH
SOCIETY

ANNUAL REPORT 2017



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MEET THE EXECUTIVE BOARD



Pictured Left to Right: VP for Public Relations, **Doug Masterson**, VP for Member Relations, **Kathy Borello**, Treasurer, **John Drymala**, President, **Jannine Cody**, Secretary, **Dave Aldrup**



From left to right: Dr. Jannine Cody, Ryan Larson, Catherine Larson, Clark Larson, and Elizabeth Cody.

A NOTE FROM THE PRESIDENT & FOUNDER

It is my pleasure to present the 2017 Annual Report for the Chromosome 18 Registry and Research Society. We've had a productive and fun filled year as I am sure you will see in these pages. Our mission; to help individuals with chromosome 18 abnormalities overcome the obstacles they face, so they may lead healthy and productive lives, has 3 facets: building community, expanding education and advancing research. Our shared vision is that one day children with chromosome 18 abnormalities will have the same aspirations and achievements in life as their siblings.

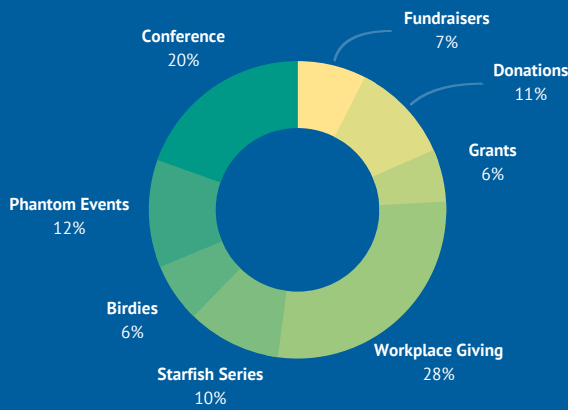
We are well aware of the enormity of that vision. But I am sure you will see in these pages that we have a clearly defined path and are making steady progress to realize that vision; and spreading a little joy in the process. The progress and the joy are both thanks to the dedication of our many members who support each other while on our path to making this vision a reality. Whether they dedicate hours or dollars or both, they make this success happen. In these pages we congratulate and appreciate their dedication. Please join us in celebrating a successful 2017.

DR. JANNINE CODY

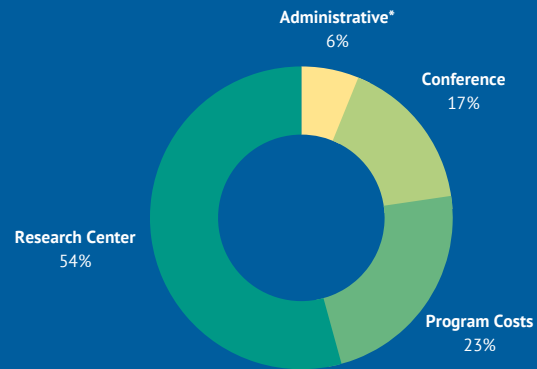
Chromosome 18 Registry & Research Society President & Founder

FINANCIAL STATEMENT

Our 2017 income and expenses at a glance. Find our 2016 I-990 tax document by clicking [here](#).



2017 Income

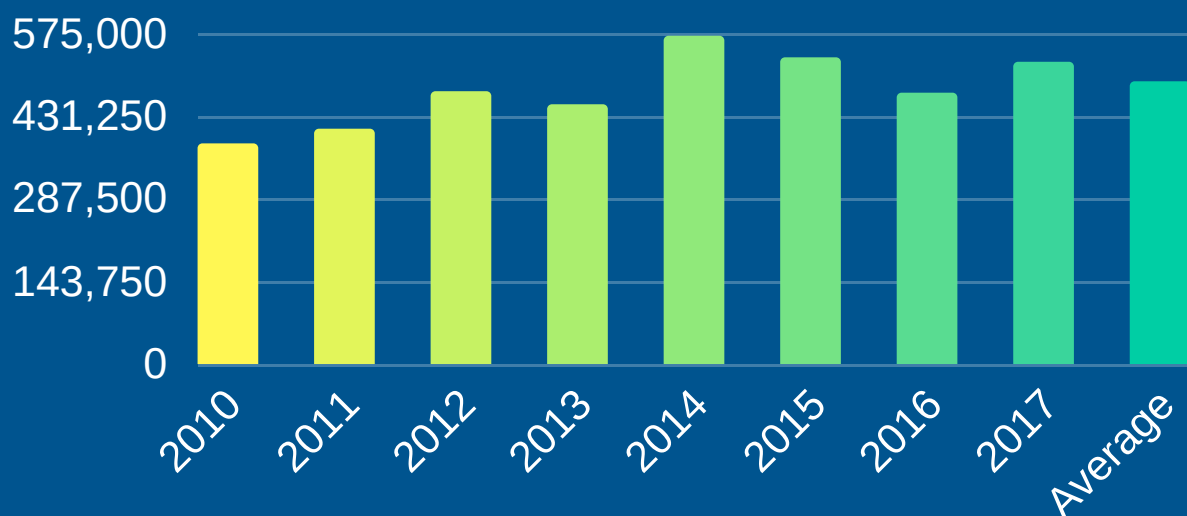


2017 Expenses

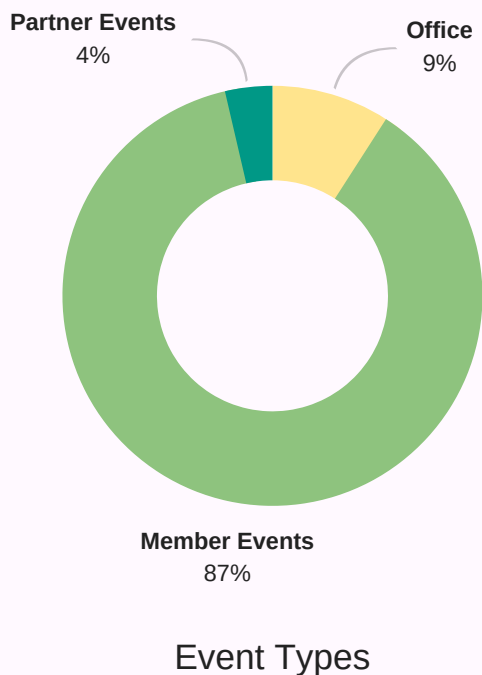
*Administrative costs include taxes, processing fees, insurance, and donor development costs.

ANNUAL INCOME

An eight year view of Chromosome 18's income at a glance. 2017 marks one of our highest incomes of the past eight years with nearly \$526,000 raised! All financial information is subject to final review during the 2017 audit.



FUNDRAISING EVENTS

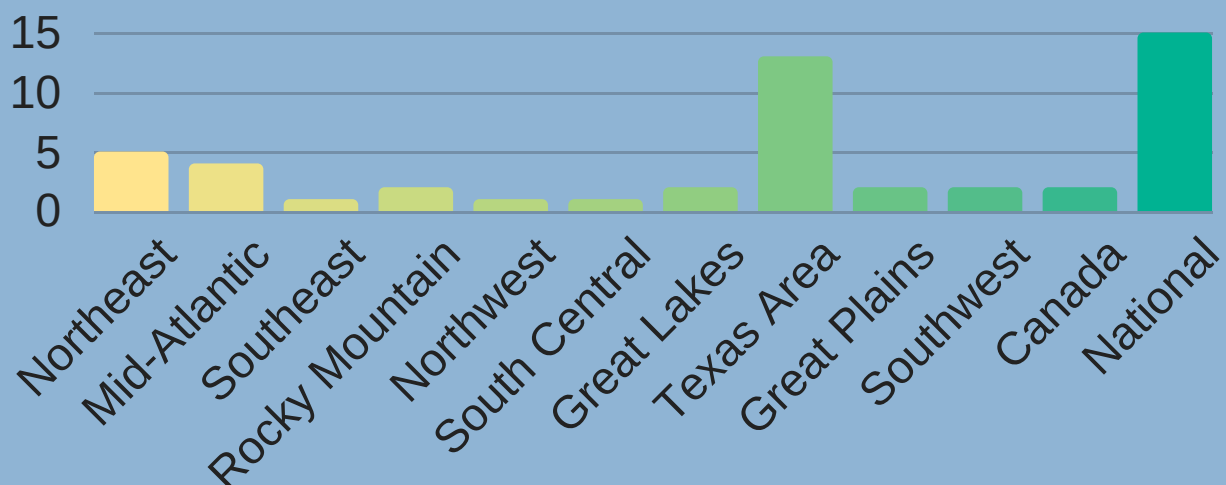


Fundraising events are one of Chromosome 18's largest funding sources. This year, 87% of these events were held by members. Fundraisers included everything from lemonade stands, to garage sales, to selling a goat! Thank you to all of our members that hold and contribute to fundraising events.

55 fundraising events in 2017

FUNDRAISING EVENTS BY REGION

Fundraisers happening across the country at the same time are represented in "National" category.



FUNDRAISING HIGHLIGHTS



The Inaugural Starfish Dash in San Antonio, Texas. An official Fiesta Event, the Starfish Dash raised over \$47,000. With over 300 participants, it was a fantastic first event in our Starfish Fundraising Series. [Click here to learn more.](#)

April 29, 2017, Start Line pictured left.

The 17th Annual Botello Lumber Golf Tournament was held in Sandwich, MA raising \$30,000 for Chromosome 18. [Click here to learn more.](#)

September 11, 2017, Neale Parker (Chromosome 18 Executive Director), Christine Granfield, Jean Ethridge, and Steven Botello pictured right.



Alex Dhanraj and John Platt raised money through a watermelon stand fundraiser this summer! Alex's sister, Gabby, has 18p-. The boys donated 100% of their sales to Chromosome 18. [Click here to learn more.](#)

June 2017, Gabby Dhanraj, Alex Dhanraj, and John Platt with their lemonade stand, pictured left.

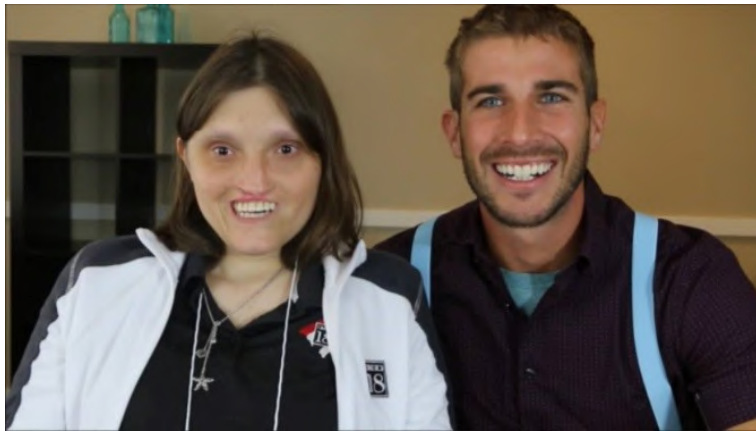
Self-Advocate, Amelia Gallardo, donated the proceeds of selling the goat she raised through 4H. Amelia raised over \$20,000 for Chromosome 18. [Read more about Amelia's amazing story here.](#)

August 2017, Amelia Gallardo with her award winning goat at the Ventura County Fair, pictured right.



Curious about other fundraising Super Stars? [Read about more of 2017's fundraising events.](#)

CHROMOSOME 18 IN THE MEDIA



On July 16, 2017, Elizabeth Cody became an internet sensation after her interview with Chris Ulmer. Featured in the Special Books for Special Kids interview series, Elizabeth received over **1.8 million views** on her video. [Watch the video!](#)

18
Facebook Live
broadcasts
&
20,000+
views on Facebook
Live videos



Dr. Jannine Cody & Elizabeth Cody featured in San Antonio Magazine



Eugenia Chang, Chicago Art Institute, & Patti Vasquez, Radio Host, at the July, Naperville Conference



Fox 29 Anchor, Kimberly Crawford, Elizabeth Cody, & Catherine Larson in a San Antonio News Interview

Dr. Jannine Cody and Elizabeth Cody were featured in a full page article by San Antonio Magazine. [Read the article here.](#)

Eugenia Chang (Chicago Art Institute) and Patti Vasquez (radio personality) represented Chicago at the Naperville Conference.

Elizabeth Cody and Catherine Larson did two interviews with local San Antonio news shows. [Watch the interviews now.](#)

CHROMOSOME 18 CLINICAL RESEARCH CENTER

Click [here](#) to read the Chromosome 18 Clinical Research Center's full annual report.

2017 HEALTHCARE HEROES AWARD WINNER: DR. JANNINE CODY

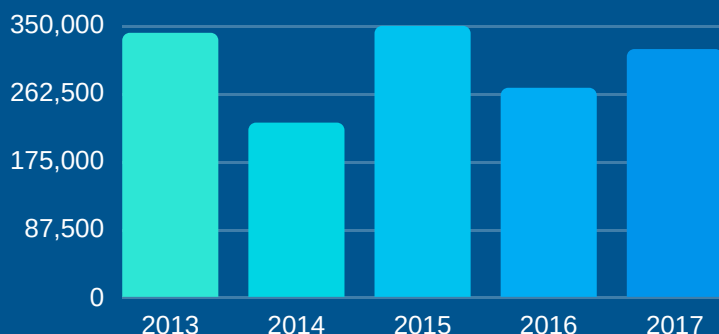


Pictured left to right: Dr. Jannine Cody, Elizabeth Cody, and Dr. William Henrich.

Dr. Jannine Cody was one of twenty 2017 Health Care Heroes recognized the San Antonio Business Journal. One of the other awardees was Dr. William Henrich, President of UT Health. The Healthcare Heroes recognize outstanding achievements by people in an industry that is vital to San Antonio.

CHROMOSOME 18 DONATIONS

The Chromosome 18 Registry & Research Society is the primary funder of Chromosome 18 Clinical Research Center. Here is a snapshot of our donations to the Chromosome 18 Clinical Research Center over the past five years.



Chromosome 18 donated

\$320,000

to the Chromosome 18
Clinical Research
Center in 2017

650

families enrolled in the
research study

26

years at the cutting edge
of research

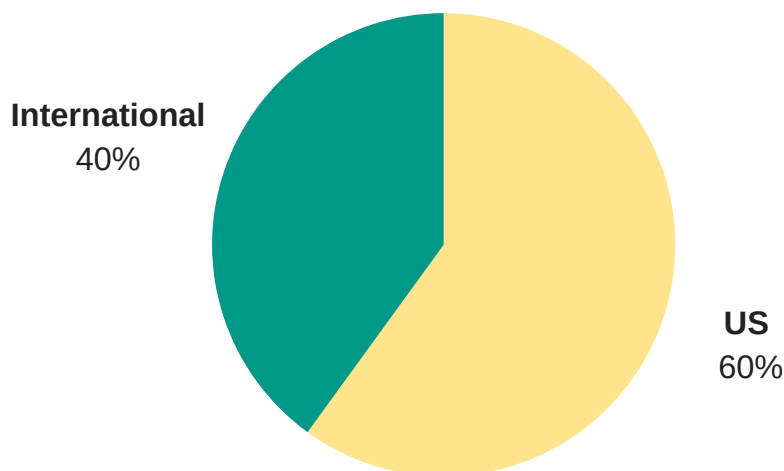
15

Chromosome 18 Clinical
Research Center Tours

8

Research Newsletters

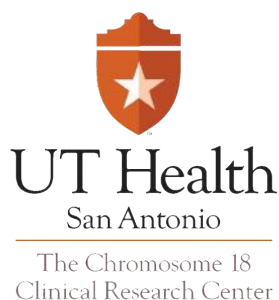
MEMBERSHIP UPDATES



This includes everyone who has subscribed to our newsletter.

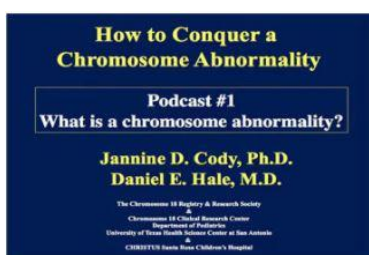
220
new families
joined
in 2017

MEMBER RESOURCES



The Chromosome 18 Clinical Research Center released their Clinical Management Guides this year, representing over 26 years of research. [Find them here.](#)

We released our Syndrome Facebook Groups this year, in addition to our Closed, Sibling, and Self-Advocate Facebook Pages as member only resources. [Click here for to find out more!](#)



Updated podcasts on all things Chromosome 18 by Dr. Jannine Cody are available on our website. [Listen to the podcasts here.](#)

CHROMOSOME 18 OFFICE



Pictured left to right: Neale Parker (Executive Director) , Emi Behan (Director of Operations, current), Leah Gransbery (Director of Operations, previous), Elizabeth Cody

Pictured left to right: Agnes Espericueta, Victoria Ochoa, Andrea Davila, Calasia Haynes, and Casey Cannon.



Chromosome 18 is proud to partner with local colleges to host 5 work study associates and interns! These part-time additions to the office focus on office administration, accounts, social media, community outreach, and grants. While the students are getting real word experience and training, Chromosome 18 is getting the benefit of increased bandwidth to do more for our families.

VOLUNTEER DIRECTORS



Director of Social Media
Stacey Gallardo



Director of Technology
Jeff Borello



Director of Marketing
Liz Woodfield

Our Volunteer Directors do not sit on the Board of Directors, but they dedicate an enormous amount of time and effort to supporting Chromosome 18. A huge thank you to their support throughout the year! We truly could not achieve our mission without them.

24TH ANNUAL CONFERENCE

Naperville, Illinois - July 12-15, 2017



Group photo of 24th Annual Chromosome 18 Conference in Naperville, Illinois - July 15, 2017.

\$25,756

Raised through VIP
Table Sponsorship

\$10,520

Raised through Silent
& Live Auctions

438

Conference Attendees

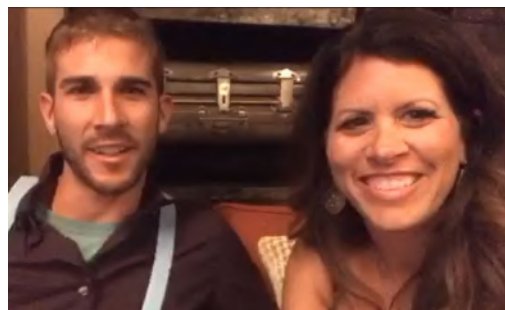
97

First-Time
Attendees

We celebrated our 24th Annual Conference at the Chicago Naperville Marriott in Naperville, Illinois. **[Read the full story here!](#)**



Conference Co-Chairs Kathy Borello (left) and Ivette Ruiz Cohen (right)



Chris Ulmer was featured as our Key Note speaker on July 15. You can view an interview with Chris & Stacey Gallardo **[here](#)**.

CHROMOSOME 18 EUROPE

Click [here](#) to visit Chromosome 18 Europe's website.



Chromosome 18 Europe is an affiliate of the Chromosome 18 Registry & Research Center. Chromosome 18 Europe holds their conference every two years. Their most recent conference was held in Rome, Italy in August 2016 (pictured above) and the next will be June 2018 in Glasgow. We are proud to partner with Chromosome 18 Europe to raise awareness and provide support for Chromosome 18 families around the world.

CHROMOSOME 18 AUSTRALASIA

Click [here](#) to visit Chromosome 18 Australasia's Facebook page.



Chromosome 18 Australasia is an affiliate of the Chromosome 18 Registry & Research Center. Chromosome 18 Australasia holds their conference every four years. Their most recent conference was held in Queensland, Australia in April 2017 (pictured above). We are proud to partner with Chromosome 18 Australasia to raise awareness and provide support for Chromosome 18 families around the world.

BOARD OF DIRECTORS

Executive Board

President	Jannine Cody
Vice President for Member Relations	Kathy Borello
Vice President for Public Relations	Doug Masterson
Treasurer	John Drymala
Secretary	Dave Aldrup

Regional Coordinators

Great Plains	Cindy Josefson
Northeast	Dave & Kim Stoddard
Rocky Mountain	Angie Moss
Southeast	Becky Hobby
Texas Area	Tam Aldrup
Great Lakes	Melanie Gorrell
Mid-Atlantic	Liz Woodfield & Mike Fudala
Northwest	Joy Wilson
South Central	Open
Southwest	Tracy Stevens

Syndrome Coordinators

Tetrasomy 18p	Marie Primeau
18q-	Katie Schilly
Trisomy 18	Jude Wolpert
Ring 18	Tanis Nicholson
18p-	Katharine Newman

Sibling Coordinator	Dalton Guthrie
Bereavement Coordinator	Charlett Korling
Self-Advocate Coordinator	Mark Sogard

Ex Officio Members

Europe	Bonnie McKerracher
Australia	Marlene Brightwell
Canada	Shelley Hunt

Not sure what your region is? [Click here for more information!](#)

THANK YOU TO OUR COMMITTEE MEMBERS

It is impossible to thank all our volunteers that help us with all our yearly events, but our committees help plan and make sure everything goes smoothly.

24th Annual Conference Committee:

Co-Chairs: Kathy Borello & Ivette Ruiz-Cohen

Tam & Dave Aldrup, Jeff Borello, Jannine Cody, Jeff & Kristen Earl, Stacey Gallardo, Racine Ghiz, Dalton Guthrie, Shelley Hunt, Mark Sogard

Inaugural Starfish Dash Committee:

Co-Chairs: Fred & Tracy Gibbons

Tam Aldrup, Karla Baker, Jannine Cody, Elizabeth Cody, Elena Castoreno, Rob Fagen, Craig Gransbery, Stacy Gallardo, Heather Hepp, Geanetta Hoxhaj, Loren McCall-Campbell, Ann Newstead, Cynthia Parsons, Mike Peck, Iris Luna Rendon, Mark Sogard, Claudia Traa

2018 EVENTS

Curious about what is coming up in 2018?

February 6, 2018 - Dr. Jannine Cody presents at Health Cell's State of the Industry

March 2018 - Birdies for Charity Fundraising, National

April 27, 2018 - Starfish Scramble, San Antonio, TX

April 28, 2018 - 2nd Annual Starfish Dash, San Antonio, TX

June 22-24, 2018 - European Biannual Conference, Glasgow, Scotland

July 2-5, 2018 - Chromosome 18 Decoded (Annual Conference) in Baltimore, MD

July 2018 - Starfish Splash, National

August 2018 - 27th Anniversary of the Chromosome 18 Clinical Research Center

December 2018 - Phantom Tea & Wine

Are you planning an event to support Chromosome 18? Contact Chromosome 18 at office@chromosome18.org to let us know!

THANK YOU TO OUR DONORS!

\$10,000 and Up:

Valero Energy Foundation
Botello Lumber Co, Inc.
Jeff & Kathy Borello
Jeff & Carol Cohen
Mike & Gina Wey
Lawrence Shepard

\$5,000 to \$10,000:

Katy Burns
University of Dallas
Daniel Schmick
Neale Parker and Cynthia Parsons
Ben & Peg Flowe
Midwest Tool & Cutlery Company
S&L Marx Foundation
Jannine Cody

\$2,500 to \$5,000:

Antoninette Cox
Tam & Dave Aldrup
Elizabeth Cody
Joel Wolf
Bettina Finn
Stacey Gallardo
Doug Masterson

\$1,000 to \$2,500:

Spencer & Jodi Hight
Les Weatherhead
Megan Wilson
Gerald & Theresa Kaiser
John Walz
Jay & Susie Goldberg
Jim & Claudia Traa
Barbara Grossman

\$1,000 to \$2,500:

Michael G. Lacey
Dave Stoddard
Scott Plummer
Roesmary Woodfield
Rhonda Bentley
Bank of America
Anita Jacks
Thomas Schilly
Grande Communications
Fred & Tracy Gibbons
Autumn Conley
Rachel Sorensen
Stephanie Stokes
Auto Nation
Mary Cohen

\$500 to \$1,000:

Michael J. Moon
Jeff Pompeo
Dave Burnes & Penny Battles
Kristen Paler
Lynn Whitmer
Brian Primeau
Camilla Downs
Letisa Berry
Beverly Cullen
Eric & Brian Dosal
Molly Feagin
Troy Haby
Chip Keichline
Patricia Lacey
John & Kristen Shepard
James Chung
Joy Cox
Cathy Gorrell

\$500 to \$1,000:

Melanie Gorrell
John Hobby
William Hill
Nishan Krikorian
Georgiana Leonard
The Good Life Foundation
Lewis Noonberg
Michael Regina
SHG Planning, Inc.
Cynthia Shepard
St. Anthony of Padua Church
PC Group

Thank you to our donors who supported Chromosome 18 in 2017 with direct donations or fundraising events. This list reflects only direct donations from individuals or corporations. We try our very hardest to ensure that everyone is recognized for their support. However, if you notice that your name is missing from the list, please contact our office at office@chromosome18.org.

THANK YOU FOR A FANTASTIC YEAR!

