

2019 ANNUAL REPORT



CHROMOSOME 18 REGISTRY & RESEARCH SOCIETY

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MEET THE BOARD OFFICERS



Pictured Left to Right, Front to Back: Treasurer, John Drymala, Secretary, Dave Aldrup, VP for Development, Liz Woodfield, President, Dr. Jannine Cody, VP for Member Relations, Katie Bailey



Pictured Left to Right: Dr. Jannine Cody, Ryan Larson, Dr. Catherine Cody Larson, Clark Larson, and Elizabeth Cody

A NOTE FROM THE PRESIDENT & FOUNDER

We have a dream; that one day children born with a chromosome 18 abnormality will grow up to be healthy and independent adults. Every year that dream becomes a little closer to reality through our comprehensive approach of building community, educating stakeholders and investing in research. This is no small task and to accomplish all of this it takes a village. In this annual report, we share some of the highlights of 2019 and the accomplishments of our village. Our village of members, volunteers, donors and staff all working together to move this dream closer to reality. We want to thank each and every person who gave of themselves in 2019.

DR. JANNINE CODY

2019 Snapshot

CHROMOSOME 18 REGISTRY & RESEARCH SOCIETY

JOINED CHROMOSOME 18 IN 2019

48

18q-
Families

27

18p-
Families

24

Trisomy 18
Families

15

Tetrasomy 18p
Families

5

Ring 18
Families

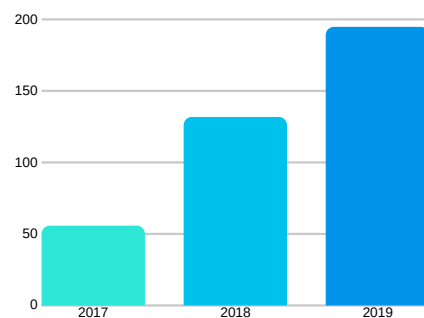
*DOES NOT INCLUDE FAMILIES
WHO SELECTED "OTHER"
AS A SYNDROME TYPE.



90%

OF PARENTS REPORT AN INCREASED
QUALITY OF LIFE FOR THEIR
CHILDREN AND THEMSELVES AFTER
JOINING CHROMOSOME 18.

**193 FUNDRAISING &
EDUCATIONAL
EVENTS IN 2019 -
A 48% INCREASE
FROM 2018!**



FUNDRAISING & MEMBER EVENTS

29 YEARS

CELEBRATING 29 YEARS OF
SERVICE TO CHROMOSOME 18
FAMILIES IN 2019. JOIN US IN
CELEBRATING 30 YEARS IN
2020!

**\$85,000 OF GRANT
FUNDING RECEIVED TO
SUPPORT CHROMOSOME
18 MEMBER SERVICES
AND RESEARCH.**

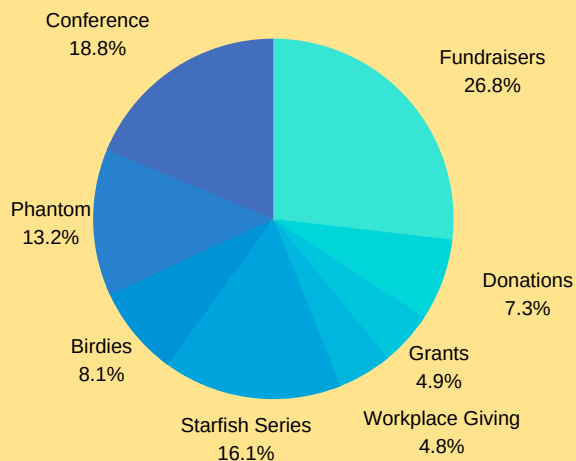
61%

**INCREASE IN
GRANTS FUNDING**

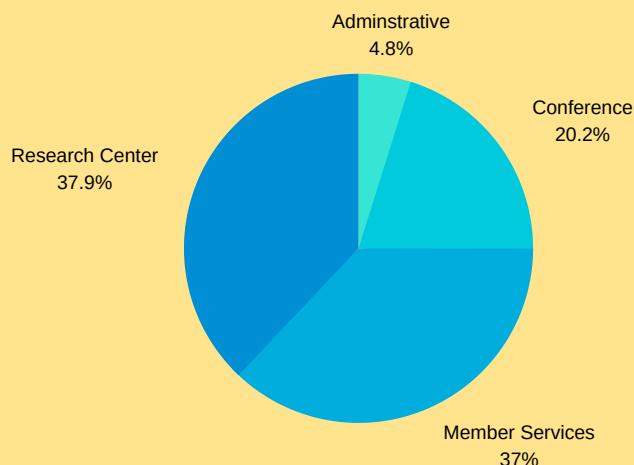
Chromosome 18

2019 INCOME AND EXPENSES AT A GLANCE

2019 INCOME



2019 EXPENSES



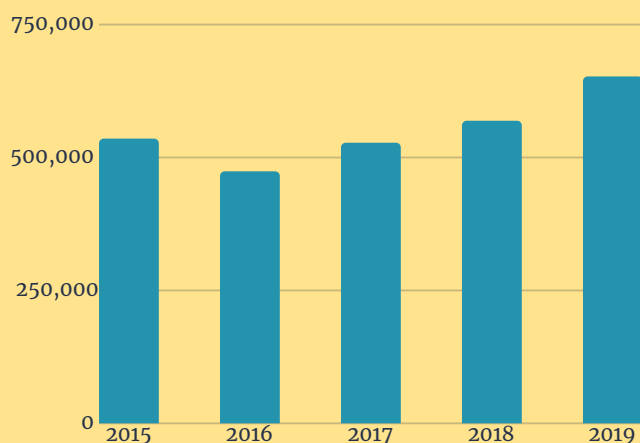
*Administrative costs include taxes, processing fees, insurance, and donor development costs.

\$38,896

**RAISED BY
FACEBOOK
FUNDRAISERS IN 2019**

This year, Chromosome 18 supporters raised over \$38,000 through Facebook fundraisers accounting for **39% of all individual fundraising!** Thank you to everyone who took the time to host a fundraiser. Interested in hosting a Facebook fundraiser? Find out more [here](#).

5-YEAR ANNUAL INCOME OVERVIEW



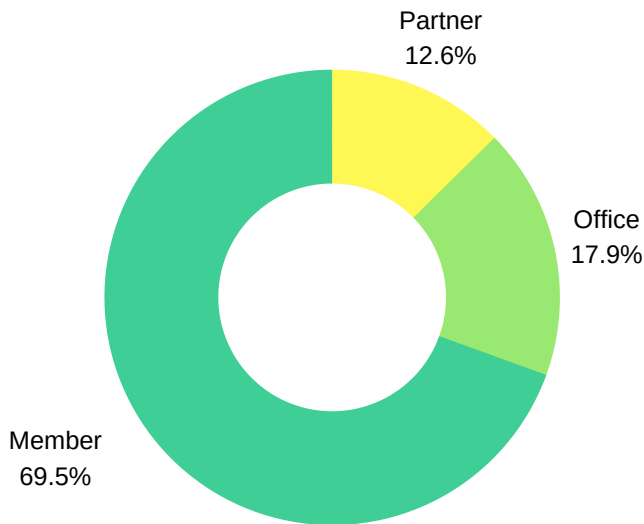
NEARLY \$651,000 RAISED IN 2019

2019 marks Chromosome 18's highest annual income in the past 5-years, with nearly \$651,000 raised! (Pending audit review).

Fundraising Events

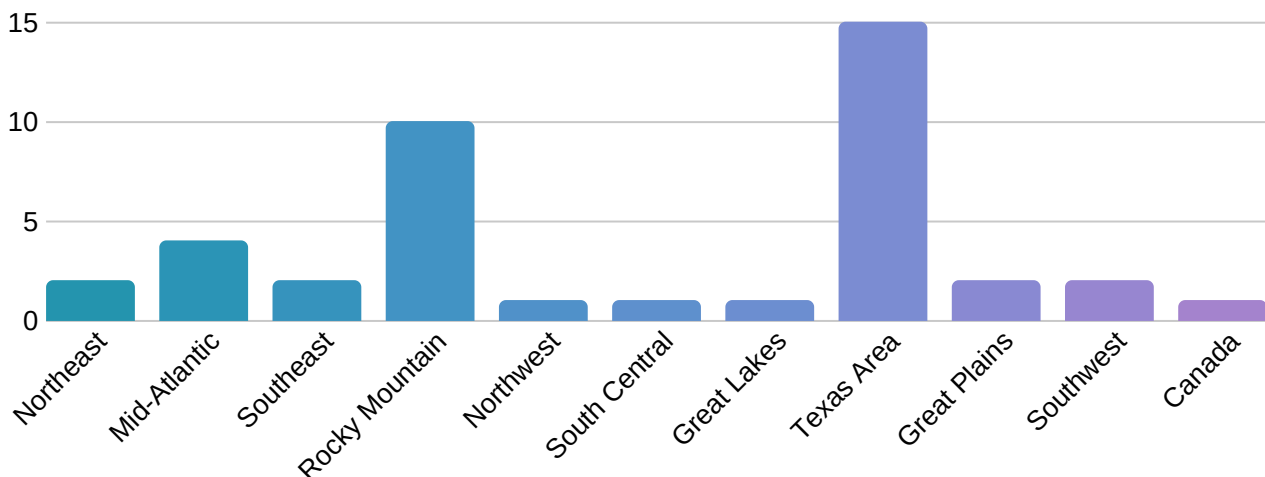
193

fundraising events were hosted by Chromosome 18 members, families, and friends in 2019. This is a 48% increase in events held in 2018. View a list of our events & fundraisers [here](#).



Fundraising events are one of Chromosome 18's largest funding sources. This year, nearly 70% of our fundraising events were held by our members. Every dollar counts, and we are grateful to our fundraisers both big and small. Thank you to everyone who held and contributed to a fundraising event in 2019!

Fundraising Events by Region



85

Birthday Fundraisers

9

Starfish Series Events

68

Regional Events

Fundraising Highlights

STARFISH SCRAMBLE EVENT SERIES



STARFISH SCRAMBLE ALEXANDRIA

On May 19, 2019, Tom & Jen Kunkel hosted a Starfish Scramble at Topgolf in Alexandria, VA. With nearly 45 people in attendance, the Kunkel family raised nearly \$3,500. Read more about the event [here](#).

STARFISH SCRAMBLE FORT WORTH

On July 8, 2019, Jodi & Spencer Hight held the Fort Worth Starfish Scramble. Over 35 participants joined in the afternoon of fun with local Chromosome 18 families. Over \$2,500 was raised. Read more [here](#).



STARFISH SCRAMBLE HOUSTON

On September 8, 2019, Tam & Dave Aldrup along with Kristy Holder, hosted a Starfish Scramble in Houston, TX. Over 60 people came together for a fun afternoon and raised over \$5,000. View more photos [here](#).

STARFISH SCRAMBLE EDISON

On October 20, 2019, Mike Fudala & Liz Woodfield co-hosted a Starfish Scramble at Topgolf in Edison, NJ. By engaging local organizations, Sprinkler Fitters and NJ Superior Officers Association, the event was able to raise over \$5,000. View photos [here](#).



STARFISH SCRAMBLE NAPERVILLE

On November 3, 2019, Kathy Borello organized and hosted the Naperville Starfish Scramble at Topgolf. With sponsorships from Andromeda, Horton Group, and TopNotch Silkscreening, as well as a silent auction, the event raised nearly \$6,000! View photos [here](#).

The Starfish Scramble Austin took place on June 2, 2019. View photos of the event [here](#).

16th Annual Golf Tournament



After a brief hiatus, the Chromosome 18 Annual Golf Tournament returned in 2019 with the help of tournament chairs, Jim & Claudia Traa. Held at the Hyatt Hill Country Golf Club in San Antonio, TX, 70 players joined over 20 volunteers for an afternoon of golf and fun. Chromosome 18 would like to thank both the Valero Energy Foundation and the Boys of 88 for their generous sponsorships. View pictures from this year's event [here](#).

4th Annual Starfish Dash



Over 350 people joined Chromosome 18 in celebrating Fiesta with the 4th Annual Starfish Dash 5K Run/Walk in San Antonio, TX. Families from across the state joined with community members for an active morning, live music, and a health & wellness fair. Don't miss out on joining us at the 5th Annual Starfish Dash on April 25, 2020, an official Fiesta event! View pictures from this year's event [here](#).

CHROMOSOME 18 CLINICAL RESEARCH CENTER

View the Chromosome 18 Clinical Research Center's 2019 Annual Report [here](#).

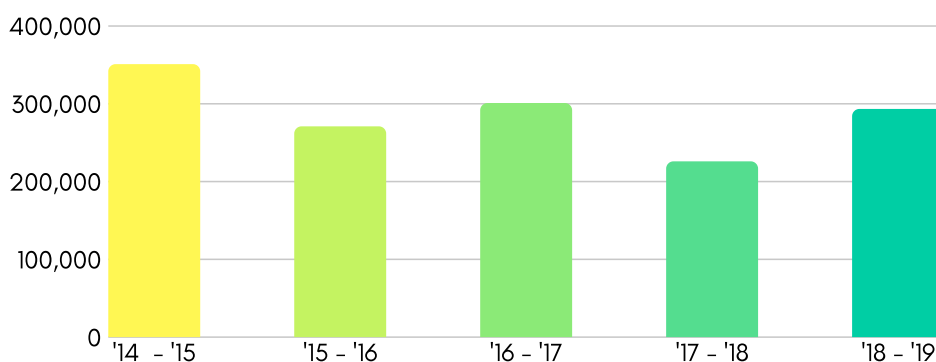
BAPTIST HEALTH AWARDED GRANT FOR CLINICAL RESEARCH CENTER EQUIPMENT



Dr. Cody and Elizabeth Cody interviewed for Baptist Health Foundation grant award.

In December 2019, the Baptist Health Foundation awarded a grant to Chromosome 18 to purchase remote monitoring devices for a project at the Chromosome 18 Clinical Research Center. As part of the grant, Dr. Cody & Elizabeth were featured in a video that was shown to San Antonio community leaders and non-profits at the award ceremony. You can view the full video [here](#). Thank you to the Baptist Health Foundation!

CHROMOSOME 18 CLINICAL RESEARCH CENTER FUNDING



5-YEAR CRC DONATION OVERVIEW BY GRANT YEAR

The Chromosome 18 Registry & Research Society is the primary funder of the Chromosome 18 Clinical Research Center. Donations to the Chromosome 18 Clinical Research Center follow the academic year. As shown in the graph above, the reduction in funding over the past 5 years to the CRC is clear, but we have made steady growth in increasing funding in the past year. With your help, we can fully fund the Chromosome 18 Clinical Research Center and their work.

689

participants enrolled in
the research study

35

new families joined
the research study

30%

increase in funds
donated to CRC from '17
to '18 academic year

28

years as the
world leader in
chromosome 18
research

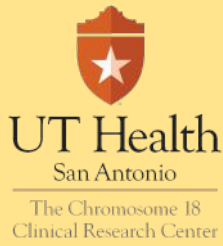
11

Research
Newsletters

10

Chromosome 18
Clinical Research
Center Tours

Membership Resources



CHROMOSOME 18 CLINICAL RESEARCH CENTER PHYSICIAN MANAGEMENT GUIDES

Released in 2017, the Physician's Management Guides summarize 28 years of research and can be shared directly with your physician or specialist. Find them [here](#).

SOCIAL MEDIA

Chromosome 18 members have access to our closed Facebook pages to connect with other families. Check out the Facebook pages [here](#).



SYNDROME & REGIONAL COORDINATORS

As part of Chromosome 18 membership, you have the opportunity to connect with volunteer Regional & Syndrome Coordinators. Find your coordinator [here](#).

ONLINE RESOURCE PORTAL

Chromosome 18 has consolidated member resources into one central location. Take a few minutes to review our resources [here](#).

Membership Survey Results

In 2019, for the first time ever, Chromosome 18 sent a member satisfaction survey to our families to receive feedback about our programs. Chromosome 18 gained valuable insights into how we are currently serving our members and how we can improve to better serve our families!

90% of parents report an increased quality of life for their children and themselves after joining Chromosome 18

of families report active engagement with Chromosome 18 resources, activities, & events

80%

Chromosome 18 Office

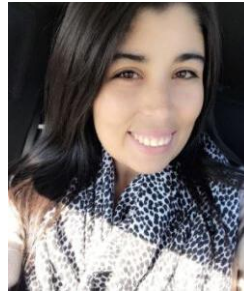
MEET THE TEAM



Neale Parker
Executive Director



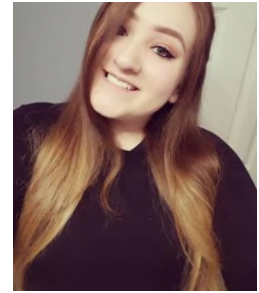
Emi Behan
Director of Operations



Victoria Ochoa
Accounts Supervisor



Agnes Espericueta
Administrative Supervisor



Andrea Davila
Social Media Supervisor



Elizabeth Cody
Office Assistant



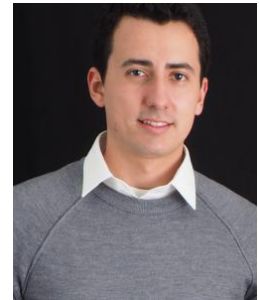
Ravee Mata
Community Assistant



Jenai Coleman
Special Projects Assistant



Gaby Miles
Administrative Supervisor



Marty Martinez
Social Media Supervisor



Joseph Casarez
Grants Intern



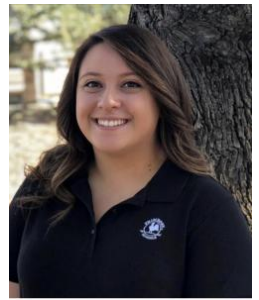
Ashley Grey
Grants Intern



Dazmine Thomas
Accounts Assistant



David Conteras
Grants Intern



Brenna Kilbride
Grants Intern



Sarah Vasquez
Administrative Assistant



Cynthia Proano
Accounts Assistant



Rafael Villegas
IT & Website Intern



Ashley Basile
Administrative Assistant



David Garza
Accounts Assistant

CHROMOSOME 18 IS PROUD TO PARTNER WITH LOCAL PROGRAMS TO HOST INTERNS AND WORK STUDY STUDENTS

Chromosome 18 works with local colleges, universities, and community programs to host internships and work-study programs. In 2019, Chromosome 18 hosted 9 work-study students and 9 interns. These part-time additions to the office focus on administration, accounts, social media, community outreach, IT, and grants. Together, our grants interns applied for 62 grants in 2019. While students are improving their professional skills, Chromosome 18 is able to better serve our members. Learn about their experiences [here](#).

CHROMOSOME 18 VOLUNTEER DIRECTORS



Jeff Borello
Director of Technology



Stacey Gallardo
Director of Social Media



Gene Johnson
Director of Data Solutions



Kristy Holder
Director of Marketing

Our Volunteer Directors are volunteer staff members, but they dedicate an enormous amount of their time and effort to supporting Chromosome 18. We are incredibly grateful for the donation of their time and talents to better serve our members. Thank you to our wonderful Volunteer Directors team! We are thankful for your contributions and hard work.

CHROMOSOME 18 ADVISORY BOARD CHAIRS

In addition to our Board of Directors, Chromosome 18 has a National Advisory Board and a local San Antonio Advisory Board. Our Advisory Board Chairs coordinate communication with board members to gain valuable insight from community members on how Chromosome 18 interacts with our local and national communities.



Liz Woodfield
National Advisory
Board Chair



Claudia Traa
San Antonio Advisory
Board Chair

425

Starfish Dinner & Dance
Attendees

415

Conference Attendees

63

Rare Bears given to self-
advocates

20

First-time families

18

Family Table Sponsorships

\$12,314

raised through silent & live
auctions

\$28,074

raised through family
table sponsorship

26th Annual Conference

COLORADO SPRINGS, CO - JULY 22-24, 2019



GROUP PHOTO OF 26TH ANNUAL CHROMOSOME 18 CONFERENCE
COLORADO SPRINGS, CO - JULY 22-24, 2019

We celebrated our 26th Anniversary of Chromosome 18 Decoded, the Annual Family Conference, in Colorado Springs, CO! Read the full story [here](#).



Conference Chairs: Angie & Robert Moss

A huge thank you to our conference chairs, Angie & Robert Moss, for making 2019's Conference a success!



Chromosome 18 partnered with Rare Bears to provide bears hand-made by volunteers to our self-advocates. Each bear, like our self-advocates, is unique!

CHROMOSOME 18 EUROPE



Chromosome 18 Europe is an affiliate of the Chromosome 18 Registry & Research Society. Chromosome 18 Europe holds their conference every two years. Their most recent conference was held in Glasgow, Scotland in June 2018 (pictured above). Their upcoming conference will be in Rome, Italy from 24-26 July 2020. We are proud to partner with Chromosome 18 Europe to raise awareness and provide support for Chromosome 18 families around the world.

Visit **Chromosome 18 Europe's website** for more information.

CHROMOSOME 18 AUSTRALASIA



Chromosome 18 Australasia is an affiliate of the Chromosome 18 Registry & Research Society. 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.

Visit Chromosome 18 **Australasia's Facebook page** for more information.

2019 Leadership

BOARD OFFICERS

President
Vice President for Member Relations
Vice President for Development
Treasurer
Secretary

Jannine Cody
Katie Bailey
Liz Woodfield
John Drymala
Dave Aldrup

DIRECTORS AT LARGE

Director at Large
Director at Large
Director at Large

Carol Cohen
Christine Puckett
Tom Kunkel

REGIONAL COORDINATORS

Great Plains
Northeast
Rocky Mountain
Southeast
Texas Area
Great Lakes
Mid-Atlantic
Northwest
South Central
Southwest

Kerry Connolly
Jason Goodman
Angie Moss
Kimberly Minor
Tam Aldrup
Melanie Gorrell
Mike Fudala
Joy Wilson
Open
Tracy Stevens

SYNDROME COORDINATORS

Tetrasomy 18p
18q-
Trisomy 18
Ring 18
18p-

Marie Primeau
Kelly Collins
Jude Wolpert
Tanis Nicholson
Katharine Newman

ADDITIONAL COORDINATORS

Sibling Coordinator
Bereavement Coordinator
Self-Advocate Coordinator

Catherine Larson
Catherine Burzio Moran
Racine Ghiz

EX-OFFICIO MEMBERS

Europe
Australia
Canada

Bonnie McKerracher
Tracy Healy
Shelley Hunt

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

Thank You, Committee Members!

It is impossible to individually thank all of our volunteers that help with our yearly events, but we want to recognize the committees that help plan our biggest events of the year!

26th Annual Conference Committee:

Chairs: Angie & Robert Moss

Tam & Dave Aldrup, Kathy & Jeff Borello, Jannine Cody, Jeff & Kristen Earl, Mike Fudala, Stacey Gallardo, Racine Ghiz, Shelley Hunt, Chrissie O'Connor, Christine Puckett, Mark Sogard, Jude Wolpert



Angie Moss, Cynthia Parsons, Alexis Garneau, & Racine Ghiz pictured with Rare Bears



2019 Starfish Dash Event, San Antonio

3rd Annual Starfish Dash Committee:

Co-Chairs: Fred & Tracy Gibbons

Tam Aldrup, Jannine Cody, Elizabeth Cody, Stacey Gallardo, Heather Hepp, Geanetta Hoxhaj, Ann Newstead, Cynthia Parsons, Mark Sogard, Claudia Traa



Jim & Claudia Traa with 2019 Golf Tournament Attendees

16th Annual Golf Tournament Committee:

Chairs: Jim & Claudia Traa

2020 Major Events

March 2020 – Champions for Charity Fundraising, National

April 6, 2020 – 30th Anniversary of the Chromosome 18 Registry & Research Society

April 25, 2020 – 4th Annual Starfish Dash, San Antonio, TX

July 6-8, 2020 – Chromosome 18 Decoded (Annual Conference) in San Antonio, TX

August 2020 – 29th Anniversary of the Chromosome 18 Clinical Research Center

September 25, 2020 – Starfish Scramble Golf Tournament, San Antonio, TX

December 2020 – Phantom Tea & Wine, National

TBD 2020 – 18 Fore 18 Golf Tournament, Tulsa, OK

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:

American Endowment Fund
Ben & Peggy Flowe
Boys of '88
Brian & Suchada McDonald
St. Luke's Health Care
Ministries
Stephen Botello & Botello
Lumber Co, Inc.
Valero Energy Foundation

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

Caryn & James Chung
Elizabeth Cody
Holly & Kyle Hubell
Jannine Cody
Jeff & Carol Cohen
Mauricio & Igal Flegman
Neale Parker & Cynthia Parsons
Tam & Dave Aldrup
The Greater New Orleans
Foundation

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

Baptist Health Foundation
Claudia & Jim Traa
Cowden Charitable
Foundation
Jeff & Kathy Borello
Katie Bailey
Kim & Dave Stoddard

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

Melanie & Jason Gorrell
Mike Fudala
Rod Hine
Terrance English
Thomas Schilly
United Way of SA & Bexar
County

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

Andrew & Lee Meyer
Anita & Dave Jacks
Annice Hill
Arizona Community
Foundation
Asel & Associates
Audi West Houston
Bailey & Will Carmack
Ben & Jan Davis
Brianna Turner
Christine & Mike Puckett
Clean Air Flooring Removal
Cynthia Wetmore
Documation
Eagle Print
Elder, Bray & Bankler, LLC
Fiesta San Antonio
Jaqueline Ngo
Jeff & Natalie Banton

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

Joe Verstreater
Jude & William Wolpert
Kelly Collins & James Bunn
Kimberly Lakowsky
Kristy Holder
Liz Woodfield & Bill
Carlucci
Lorna Feijoo & Nelson
Madrigal & the
Feijoo Ballet School
Doug & Julie Masterson
Matthew Brown
Mike Rush
Pat & Devon Lacey
Pledgling Foundation
Rod Hine
Tom & Denise Parker
UT Health San Antonio
Yvonne Lisella

\$500 to \$1,000:

Andrea Pagenkopf
Ann Newstead
Annemarie Weatherhead
Autumn Conley
Boyd & Carla Baker
Brayden Lipps
Brian Leivo
Capital Group Co. Charitable
Foundation

\$500 to \$1,000:

Connie Hubbell
Fidelity Charitable
Guy Wink
Horton Insurance
Jeannie Gibson
Jennifer Hale
Mike & Gina Wey
Jordan Oland
Joseph Caffarini
Kelly Castella
Kim Lasowski
Leah Lovitt
Lee Mabie
Martha Hobby
Mike Rush
Nina Lewis
Pat Bailey
Pershing LLC
Robert Griffice
Ross Mitchell
Scott Greenbauer
Sharing the Good Life
Foundation
Stepahnie Bulak
Susan Blackwell
Verizon, Inc.

Thank you to our donors who supported Chromosome 18 in 2019 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.

Chromosome 18 Champions

THANK YOU TO OUR MONTHLY DONORS

Erin Harlan
Patricia Lacey
Eileen Hossenloop
Casey Baker
Michael Fudala
Michael & Karen Todd
Lorna Feijoo
Nathaniel Kelly
Shelby Griffin

Dave Aldrup
Jannine Cody
Paula Smith-MacDonald
Catherine Burzio Moran
Kelly Collins
Rob Sims
Brandon Bennett
Katharine Sprister

Thank you to our donors who supported Chromosome 18 in 2019 through monthly recurring donations. This list only reflects individuals who give directly to Chromosome 18, not members who give through employee giving programs. 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, Valero Energy Foundation!

Thank you to Valero Energy Foundation for their continued support over the past two decades! Valero Energy Foundation and their staff have donated their time & resources to help make our member events a success. Thank you to the Valero Energy Foundation for your help and support! Learn more about the Valero Energy Foundation [here](#).



Thank You for a Fantastic Year!

