

# CHROMOSOME 18 REGISTRY & RESEARCH SOCIETY



ANNUAL REPORT  
2018





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## MEET THE EXECUTIVE BOARD



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





**Pictured Left to Right(Top):** Neale Parker, Liz Woodfield, Andrea Davila, Jannine Cody, Katie Bailey, Dave Aldurp, John Dymala  
**Pictured Left to Right (Bottom):** Calasia Haynes, Agnes Espericueta, Elizabeth Cody, Emi Behan, Victoria Ochoa, Casey Cannon

## A NOTE FROM THE EXECUTIVE DIRECTOR

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Chromosome 18 is changing for the better! Much of the information contained within this Annual Report has been put together by our young, dynamic staff & volunteers who are getting experience in their first professional role. Because of this, it brings a unique set of benefits, as well as some challenges to the organization; however, under the wonderful direction of Emi Behan, our team has grown substantially without any additional overhead. This is a truly unique accomplishment that has enabled many new initiatives to be put into action and brought about some financial increases, but we still have much more room to grow.

We are striving to improve what works best for our members and when necessary pivot with the constantly changing Chromosome 18 family needs. As we moved through 2018, we managed to continually develop the fun, but informative, Live Broadcasts, linking people across the country and around the world while continuing the 28-year legacy of building our community connections. Making a difference cannot happen without all of our families, volunteers, foundations, sponsors, and supporters having a passion for making a change from the status quo. With the Chromosome 18 Clinical Research Center being the only dedicated Global Research Center for Chromosome 18, we continue to support this amazing resource for our families to help with their needs now and long into the future.

It is my honor & pleasure to be a part of the innovative team as we move forward with many new programs in 2019. Thank you to everybody that has helped push the organization forward during the year.

If you don't help, who will?

**NEALE PARKER**

## A NOTE FROM THE DIRECTOR OF OPERATIONS

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Chromosome 18's mission is to help individuals with chromosome 18 abnormalities overcome the obstacles they face, so they may lead happy, healthy, and productive lives. As I near two years with Chromosome 18, I am incredibly thankful to be part of an organization that is dedicated to improving the lives of so many families around the world. Attending my first annual conference in 2018 was an incredible experience, and I was grateful for an opportunity to meet many of our families in person for the first time. Thank you for the opportunity to work toward our mission alongside each and every one of you. We cannot complete this important work without you, our members & our supporters. Please enjoy this annual report as a snapshot of the impact you've made over the past year!

**EMI BEHAN**



# 2018 Snapshot

## CHROMOSOME 18 REGISTRY & RESEARCH SOCIETY

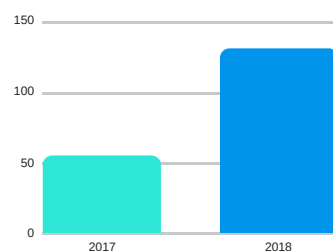
CHROMOSOME 18 CELEBRATED 25 YEARS OF ANNUAL CONFERENCES IN 2018. CHROMOSOME 18 CELEBRATED ITS 25TH ANNUAL CONFERENCE IN BALTIMORE, MD OVER THE 4TH OF JULY WEEKEND.

**25**  
**YEARS**

**71%**

INCREASE IN FUNDS RAISED FOR THE SAN ANTONIO STARFISH DASH IN 2018. \$32,580 WAS RAISED IN 2018 COMPARED TO \$19,000 RAISED IN 2017!

INCREASE FROM 55 TO 131 FUNDRAISING & EDUCATIONAL EVENTS IN 2018 HELD BY MEMBERS, COMMUNITY PARTNERS, AND CHROMOSOME 18



FUNDRAISING EVENTS

CHROMOSOME 18'S TEAM OF GRANTS INTERNS APPLIED FOR 40 GRANTS IN 2018, RESULTING IN OVER \$25,000 OF FUNDING RECEIVED TO SUPPORT CHROMOSOME 18 MEMBER SERVICES AND RESEARCH.

**40**  
**GRANTS**

**18**

Trisomy 18  
Families

**7**

Ring 18  
Families

**15**

Tetrasomy 18p  
Families

**45**

18q-  
Families

**28**

18p-  
Families

### JOINED CHROMOSOME 18 IN 2018

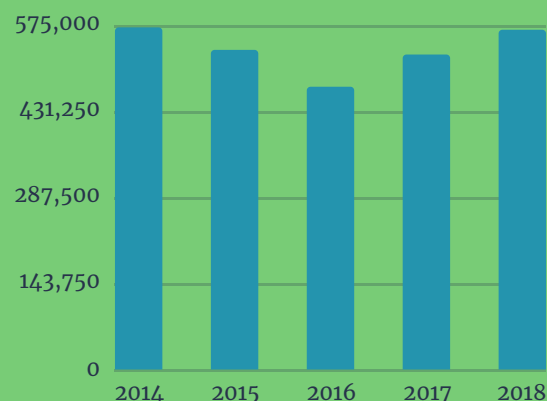
\*DOES NOT INCLUDE FAMILIES WHO SELECTED "OTHER" AS A SYNDROME TYPE.



# Chromosome 18

## 2018 INCOME AND EXPENSES AT A GLANCE

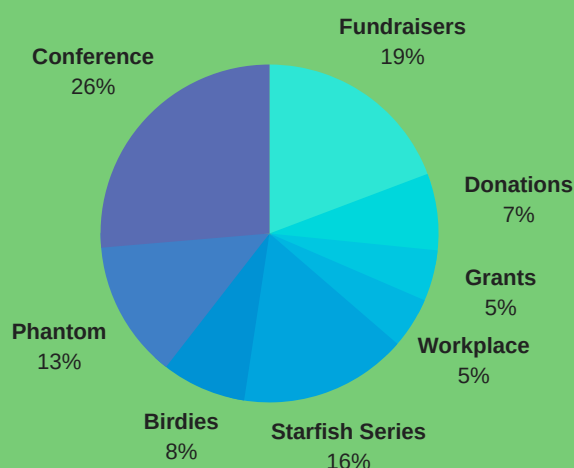
5-YEAR ANNUAL INCOME OVERVIEW



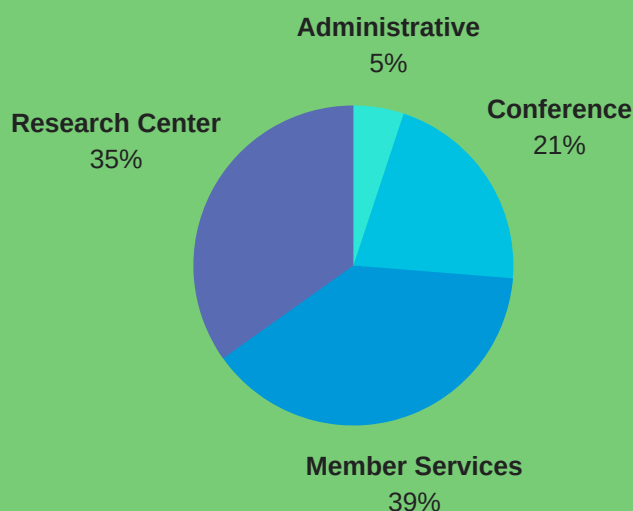
## NEARLY \$568,000 RAISED IN 2018

2018 marks Chromosome 18's second highest annual income in the past 5-years, with nearly \$568,000 raised! All financial information is subject to final review in the 2018 audit.

2018 INCOME



2018 EXPENSES



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

# \$38,210

## RAISED BY FACEBOOK FUNDRAISERS IN 2018

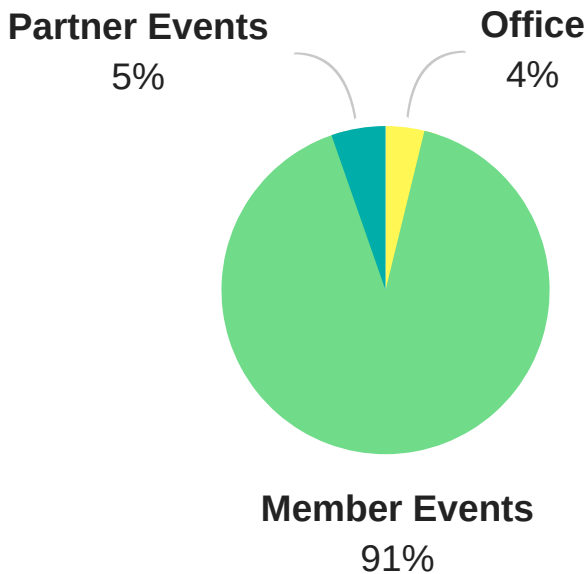
This year, Chromosome 18 supporters raised over \$38,000 through Facebook fundraisers accounting for **42% of all individual fundraising!** Thank you to everyone who took the time to host a fundraiser. Interested in hosting a Facebook fundraiser? Find out more [here](#).



# Fundraising Events

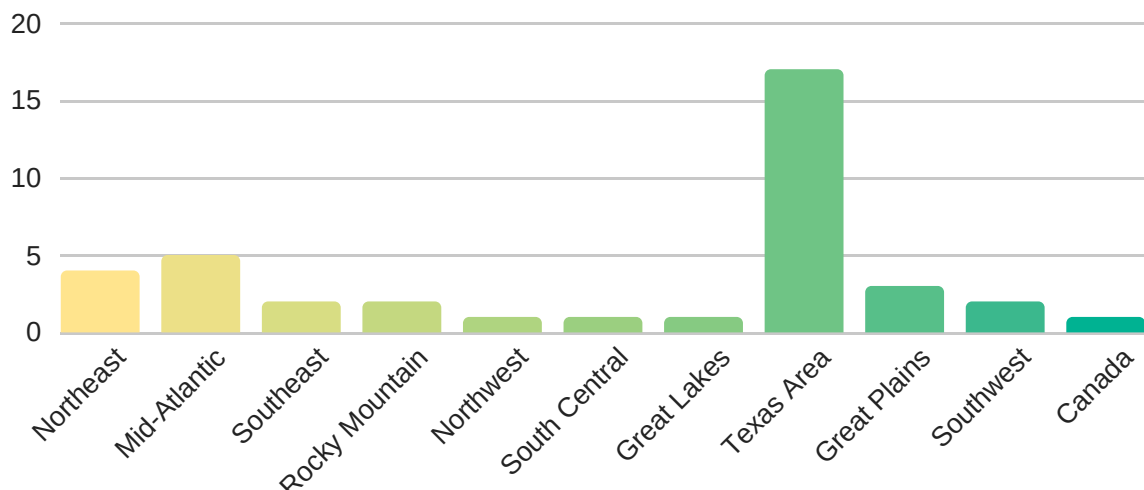
131

fundraising events were hosted by Chromosome 18 members, families, and friends in 2018. This is over twice as many events as held in 2017. View a list of our events & fundraisers [here](#).



Fundraising events are one of Chromosome 18's largest funding sources. This year, over 90% 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 2018!

## Fundraising Events by Region



70

Birthday Fundraisers

12

Starfish Series Events

66

Regional Events

\*SOME EVENTS ARE REFLECTED IN MULTIPLE CATEGORIES



# Fundraising Highlights

## STARFISH SCRAMBLE EVENT SERIES



### STARFISH SCRAMBLE SAN ANTONIO

On April 27, 2018, over 30 participants joined the fun in San Antonio for a Starfish Scramble at Topgolf the night before the Starfish Dash. With the help of Title Sponsor, Valero Energy, nearly \$12,500 was raised. Read more [here](#).

### STARFISH SCRAMBLE HOUSTON

On May 6, 2018, Tam Aldrup, with support from Kristy Holder, held the Houston Starfish Scramble. Over 40 participants joined in the afternoon of fun sponsored by Audi West Houston. Nearly \$7,500 was raised. Read more [here](#).



### STARFISH SCRAMBLE TULSA

Kyle & Holly Hubbell organized the 18 Fore 18 Tournament in memory of Jay T. Parker on May 17, 2018. Planning to make the tournament an annual event, the Hubbell family engaged the community and raised nearly \$10,000! Read more about the event [here](#).



### STARFISH SCRAMBLE EDISON

On October 21, 2018, 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 \$6,000. Read more [here](#).



### STARFISH SCRAMBLE NAPERVILLE

On November 4, 2018, 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 \$11,000! Read more [here](#).





# 659

participants enrolled in the research study

# 27

years as the world leader in chromosome 18 research

# 14

new families joined the research study

# 10

Chromosome 18 Clinical Research Center Tours

# 9

Research Newsletters

# 3

scientific publications in 2018

## CHROMOSOME 18 CLINICAL RESEARCH CENTER

View the Chromosome 18 Clinical Research Center's [2018 Annual Report](#).

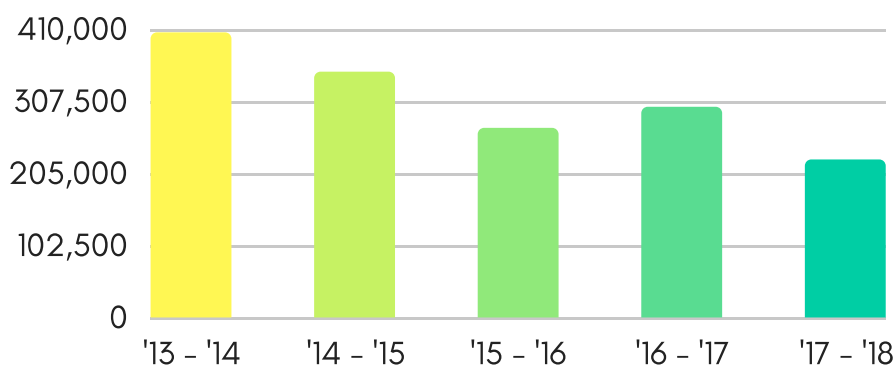
### 2018 HEALTH CELL STATE OF THE INDUSTRY



Dr. Cody pictured at the 2018 Health Cell Event.

Dr. Cody was honored at the Health Cell State of the Industry Event in February 2018. Selected as one of five honorees, Dr. Cody shared the story of the Chromosome 18 Registry & Research Society & the Chromosome 18 Clinical Research Center as one of the most inspiring and important things happening in San Antonio's bioscience and healthcare industry. You can view Dr. Cody's presentation [here](#).

### REDUCTION OF 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. While \$150,000 was donated in January 2019, the overall trend of funding is declining. This can be reversed with your help.



# Membership Updates

WELCOME TO THE FAMILY!

# 191

new families joined Chromosome 18 in 2018! We were excited to welcome families from all syndrome groups and from countries around the world!

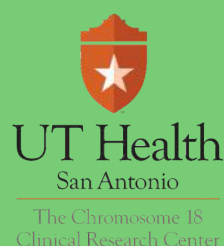
43% of our new families were international families from countries around the world.

# 43%

# 18q-

was the largest syndrome group, with 44 families listing 18q- as their syndrome.

## Membership Resources



### CHROMOSOME 18 CLINICAL RESEARCH CENTER PHYSICIAN MANAGEMENT GUIDES

Released in 2017, the Physician's Management Guides summarize 27 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](#).

### FACEBOOK LIVE

On the 18th of every month, Chromosome 18 hosts a live broadcast on a variety of topics. View past videos [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](#).





# Chromosome 18 Office

## MEET THE TEAM



Neale Parker  
Executive Director



Emi Behan  
Director of Operations



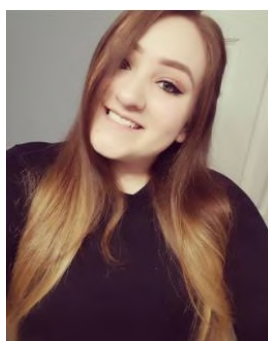
Agnes Espericueta  
Administrative Supervisor



Victoria Ochoa  
Accounts Supervisor



Elizabeth Cody  
Office Assistant



Andrea Davila  
Social Media Supervisor



Ravee Mata  
Community Outreach



Alex Lopez  
Community Outreach



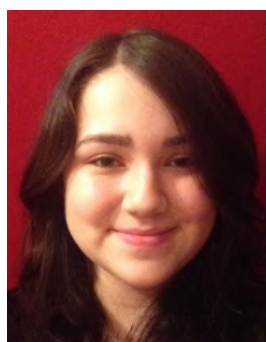
Laura Theavos  
Grants Assistant



Noemi Rodriguez  
Grants Intern



Jenai Coleman  
Grants Intern



Alexis Arispe  
IT Intern

## 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 2018, Chromosome 18 hosted 6 work-study students and 8 interns. These part-time additions to the office focus on administration, accounts, social media, community outreach, IT, and grants. While students are improving their professional skills, Chromosome 18 is able to better serve our members.



# 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 do not sit on the Board of Directors, 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 incredibly grateful for you.

# 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



Raul Flores  
San Antonio Advisory  
Board Chair



# 25th Annual Conference

BALTIMORE, MD - JULY 2-4, 2018



GROUP PHOTO OF 25TH ANNUAL CHROMOSOME 18 CONFERENCE  
BALTIMORE, MD - JULY 2-4, 2018

We celebrated our 25th Anniversary of Chromosome 18 Decoded, the Annual Family Conference, in Baltimore, Maryland over the 4th of July weekend! Read the full story [here](#).



## Conference Chair: Nichole McVicker

A huge thank you to our conference chair, Nichole McVicker, for making 2018's Conference a success!



The night ended with a bang, as conference attendees enjoyed a firework display on July 4th over the Baltimore Harbor after the Starfish Dinner & Dance.

# \$24,449

raised through VIP  
table sponsorship

# \$10,164

raised through silent & live  
auctions

# 360

Conference Attendees

# 385

Starfish Dinner & Dance  
Attendees

# 39

Sessions

# 20

First-time families

# 13

VIP Table Sponsorships



# 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). 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.



# 2018 Board of Directors

## EXECUTIVE BOARD

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

Jannine Cody  
Katie Bailey  
Liz Woodfield  
John Drymala  
Dave Aldrup

## REGIONAL COORDINATORS

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

Kerry Connolly  
Dave & Kim Stoddard  
Angie Moss  
Becky Hobby  
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  
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!

## 25th Annual Conference Committee:

### **Chair: Nichole McVicker**

Tam & Dave Aldrup, Kathy & Jeff Borello, Jannine Cody, Jeff & Kristen Earl, Denise Parker, Stacey Gallardo, Racine Ghiz, Shelley Hunt, Mark Sogard



Denise Parker & Nichole McVicker pictured at 2018 Conference with a Conference Attendee.



2018 Starfish Dash Event, San Antonio

## 2nd Annual Starfish Dash Committee:

### **Co-Chairs: Fred & Tracy Gibbons**

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

## 2019 Major Events

**March 2019** – Birdies for Charity Fundraising, National

**April 27, 2019** – 3rd Annual Starfish Dash, San Antonio, TX

**July 22-24, 2019** – Chromosome 18 Decoded (Annual Conference) in Colorado Springs, CO

**August 2019** – 28th Anniversary of the Chromosome 18 Clinical Research Center

**October 11, 2019** – Starfish Scramble Golf Tournament, San Antonio, TX

**December 2019** – Phantom Tea & Wine, National

Are you planning an event to support Chromosome 18? Contact Chromosome 18 at [office@chromosome18.org](mailto:office@chromosome18.org) to let us know!



# THANK YOU TO OUR DONORS!

## **\$10,000 and Up:**

Valero Energy Foundation  
Silicon Valley Community  
Foundation  
Botello Lumber Co, Inc.  
Ben & Peggy Flowe  
Melanie Gorrell  
Mike & Gina Wey

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

Jannine Cody  
Elizabeth Cody  
Stacy Gallardo  
Dan Schmick  
Neale Parker & Cynthia  
Parsons  
Putte Barnes  
Marilyn De Mars  
James Better  
Paula Kimberlin  
S&L Marx Foundation  
Fidelity Brokerage  
Snow Family Trust  
Peter Sullivan  
Jude & Bill Wolpert

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

Amgen Foundation  
Patricia Lacey  
Amy Kinsey  
Kathy & Jeff Borello  
Dave & Tam Aldrup  
Beverly & Michael Vogt  
Carolyn Petit  
Liz Woodfield  
Mike Furguele  
Erin Geiger  
Toni Cox  
United Way

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

Kristy Holder  
Michael Fudala

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

Thomas Chilly  
Katie Bailey  
Jim & Claudia Traa  
Fiesta San Antonio  
Rosemary Woodfield  
Barbara Grossman  
Jeff & Carol Cohen  
Bettina Finn  
Gerald Kaiser  
Megan Wilson  
Just Give  
Bank of America Charitable  
Foundation  
Scott Plummer  
Judie Heggie  
Joy Wilson  
Ave Maria Mutual Funds  
Audi West  
James Dennis  
Sprinkler Fitters Local  
Union #692  
Erica Freund  
Lorna Feijoo  
Rock-It Transport  
Halo Branded Solutions  
Kelly Collins  
Natalie Banton  
Jay Goldberg  
Middlesex United Way  
Thomas Kallai  
Sigma Gamma Delta Benley  
University

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

Carol Ann Edwards  
Ivette Cohen  
Joseph Corda  
Bill Guthrie  
Annie Katsiavelos  
Judy LaFrombois  
Doug Masterson  
Pamela Potts  
UT Health San Antonio  
Texas Women's University  
Stephanie Stokes  
Whataburger  
Joy Cox

## **\$500 to \$1,000:**

Tammy Clermont  
Jeff Pompeo  
Jamie Jackson  
Your Cause Employee Giving  
Lani Farr  
Tracy Gibbons  
Kendra Scott Jewlery  
Carol Diehl  
George Dunham  
Alycia Alongi  
Bristol Myers Squibb  
Foundation  
Connie Hubbel  
JPMorgan Chase Bank  
TRUiST  
Wayne MacMasters  
Kristin Palmer  
Lee Mabie  
William Hill  
Fred Kiser II  
Catherine Potts  
Brian Primeau  
Cynthia Wetmore  
Vito Ciminello

## **\$500 to \$1,000:**

Top-Notch Silkscreening  
Kamilah Lucas  
Terry Turner  
Scott Almhjell  
Jose Losoya  
Steven Larson  
Rachel Sorenson  
Carolyn Zaletsky  
United Airlines  
American Endowment  
Foundation  
Bottenberg & Associates  
Geri Bradley  
Emel Erel  
US Charitable Gift Trust  
Greater Houston Community  
Foundation  
Dan Hale  
Donald Hughes  
Thomas Immenschuh  
JE Clark II Corporation  
Jobber Petroleum Products  
Lewis Noonberg  
Chevron Employee Funds  
Morgan Stanley  
Jennifer Oltmans  
Mike Regina  
Todd Shivley  
Stuart Lollis  
Travelers Cyber Grants  
Chadwick Watson  
Diana Winston  
Dawn Yeingst  
Kimberly Laskowski

Thank you to our donors who supported Chromosome 18 in 2018 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](mailto:office@chromosome18.org).



# Chromosome 18 Champions

## THANK YOU TO OUR MONTHLY DONORS

Erin Harlan  
Patricia Lacey  
Eileen Hossenloop  
Casey Baker  
Sergio Arce  
Michael Fudala  
Karen Todd  
Lorna Feijoo

Dave Aldrup  
Jannine Cody  
Paula Smith-MacDonald  
Catherine Burzio  
Kelly Collins  
Rob Sims  
Sheila Sutton

Thank you to our donors who supported Chromosome 18 in 2018 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](mailto:office@chromosome18.org).

## Thank You, Andromeda Technology Solutions!

Thank you to Andromeda Technology Solutions for their donation of time and services for hosting and managing Chromosome18.org and helping us to launch our Chromosome 18 Shop online store in 2018. Chromosome 18 Member and President of Andromeda Technology Solutions, Jeff Borello, has generously donated his company's time and resources to Chromosome 18's web development and hosting needs. Thank you to Andromeda and Jeff for your help and support! Learn more about Andromeda [here](#).





# Thank You for a Fantastic Year!

