STRENGTH+ RESILIENCE



2020 ANNUAL REPORT
CHILDREN'S CARDIOMYOPATHY FOUNDATION



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A CAUSE FOR TODAY . . . A CURE FOR TOMORROW



FOUNDER'S LETTER



Dear Friends,

2020 has been a year like no other. It has been eventful and challenging with a global pandemic, racial injustice, and political tensions in the background. Even with these disruptions, the Children's Cardiomyopathy Foundation (CCF) remained focused on its core mission of supporting children with cardiomyopathy. We adapted to the circumstances with strength and resilience—coming together during a period of uncertainty and isolation. As we reflect on this turbulent year, we are grateful that we have weathered the storm and are able to continue serving the pediatric cardiomyopathy community.

In spite of this year's obstacles, we were able to make an impact in several areas:

- COVID-19 Response: CCF quickly responded to conflicting information on COVID-19 by providing reliable and pertinent health information on our website and taking the initiative to collect data on the impact of COVID-19 on children with cardiomyopathy.
- **Education**: Two new educational materials were developed: an Arrhythmogenic Cardiomyopathy insert and a Pediatric Heart Failure Guidebook in collaboration with specialists from 13 medical centers across the U.S. and Australia. Additionally, both resources were translated into Spanish.
- Advocacy: Working with family members and legislators, CCF took the lead in getting two cardiomyopathy-related bills introduced. The SAFE PLAY Act was introduced during National Heart Month in the House and Senate, and the Cardiomyopathy HEARTS Bill was a bipartisan bill introduced in the House of Representatives during Sudden Cardiac Arrest Month.

In 2020, we persevered and were able to adapt thanks to our donors and supporters. We stayed strong and forged ahead with projects to support the patient/family and medical/healthcare community.

Sincerely.

Lisa Yue

Lisa Yue

Founding Executive President

FOUNDATION OVERVIEW

The mission of the Children's Cardiomyopathy Foundation (CCF) is to accelerate the search for causes and cures for pediatric cardiomyopathy through increased research, education, awareness, and advocacy, and to support families whose children are affected by the disease.

DISEASE FOCUS

- Dilated Cardiomyopathy (DCM)
- Hypertrophic Cardiomyopathy (HCM)
- Restrictive Cardiomyopathy (RCM)
- Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)
- Left Ventricular Noncompaction Cardiomyopathy (LVNC)



BOARD OF DIRECTORS

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Brian Nold

Treasurer

Raymond Yue

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Won Choi

Carney Hawks

Carolyn Kong

Eddie Yu

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Steve Colan, M.D.

Boston Children's Hospital

Daphne Hsu, M.D.

Children's Hospital at Montefiore

Steve Lipshultz, M.D.

University at Buffalo School of Medicine and Biomedical Sciences

Shelley Miyamoto, M.D.

Children's Hospital Colorado

Joseph W. Rossano, M.D., M.S. Children's Hospital of Philadelphia

Jeff Towbin, M.D.

Le Bonheur Children's Hospital

CCF STAFF

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Founding Executive Director

Lisa Maher

Director of Development

& Communications

Caryn Anatriello

Director of Patient

Outreach & Support

Cindy Andrake

Manager of Family Support

Janine Burke

Manager of Medical Outreach

Lauren Zenreich

Administrative Manager & Bookkeeper

COVID-19 RESPONSE

The Children's Cardiomyopathy Foundation (CCF) responded to the COVID-19 pandemic by providing **reliable sources of information** to families of children with cardiomyopathy and taking the **initiative to collect data** on the impact of this novel virus on children with cardiomyopathy.

COVID-19 RESOURCES

WEB RESOURCES

 Provided relevant information on CCF Connect and a dedicated webpage of resources.

WEBINARS

Hosted 4 webinars for the CCF community.

COVID-19 Updates for Cardiomyopathy Families

Daphne Hsu, M.D. & Neha Bansal, M.D.

Research Study Update: Psychological Stress in Pediatric Cardiac Patients and Caregivers During COVID-19

Melissa Cousino, Ph.D. & Kurt Schumacher, M.D., M.S.

Emotional Considerations for Pediatric Cardiomyopathy Families During COVID-19 and Beyond

Debra Lefkowitz, Psy.D.

COVID-19 Information and Updates

Daphne Hsu, M.D. & Margaret Aldrich, M.D.

SURVEYS

- Distributed an online survey to 2,260 patients and 590 physicians. Findings were shared with the medical community to provide baseline information and guidance on COVID-19 treatment for children.
- Collaborated with the University of Michigan on an international COVID-19 survey to determine the impact on congenital heart disease care and related psychological stress.





STRENGTH IN RESEARCH

STRENGTH IN RESEARCH

Through CCF's ongoing partnership with the **National Institutes of Health-funded Pediatric Cardiomyopathy Registry**, research projects moved forward, and completed manuscripts were submitted to various peer-reviewed journals.

Funding for **new studies** were put **on hold** due to financial constraints imposed by the coronavirus pandemic.

Findings from **CCF-funded studies** were presented at several medical meetings and published in a number of peer-reviewed **scientific** and **medical journals**.



MEDICAL PRESENTATIONS

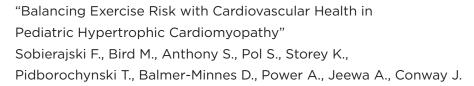
"Perceived Barriers to Medication Adherence in Pediatric Cardiomyopathy: Child & Parent Perspectives" Mirbod V., Wijesekera K., Aralis H., Barrera W., Sinclair M., Kiff C., Alejos J., Lester P.

American Psychological Association Convention Philadelphia, PA, August 2020



"Distinct Biomarker Profiles for Pediatric and Adult Dilated Cardiomyopathy" Gropler M., Lipshultz S.E., Wilkinson J.D., Towbin J.A., Colan S.D., Canter C.E., Lavine K.J., Simpson K.E.

American Heart Association Scientific Sessions Virtual, November 2020



American Heart Association Scientific Sessions Virtual, November 2020



TOP TO BOTTOM:

Patricia Lester, M.D.

Kathleen Simpson, M.D.

Jennifer Conway, M.D., F.R.C.P.C.

STRENGTH IN RESEARCH

SCIENTIFIC AND MEDICAL PUBLICATIONS

"Cardiovascular Diseases in Survivors of Childhood Cancer"
Bansal N., Blanco J.G., Sharma U.C., Pokharel S., Shisler S., Lipshultz S.E.

Cancer and Metastasis Reviews February 2020

"Reversible Mitochondrial Fragmentation in iPSC-Derived Cardiomyocytes from Children With DCMA, a Mitochondrial Cardiomyopathy"
Rohani L., Machiraju P., Sabouny R., Meng G., Liu S., Zhao T., Iqbal F., Wang X., Ravandi A, Wu J.C., Khan A., Shutt T., Rancourt D., Greenway S.C.

Canadian Journal of Cardiology April 2020

"Elevated Heart Rate and Survival in Children with Dilated Cardiomyopathy: A Multicenter Study from the Pediatric Cardiomyopathy Registry" Rossano J., Kantor P.F., Shaddy R.E., Shi L., Wilkinson J.D., Jefferies J.L., Czachor J.D., Razoky H., Wirtz H.S., Depre C., Lipshultz S.E.

Journal of the American Heart Association July 2020

"Distinct Biomarker Profiles for Pediatric and Adult Dilated Cardiomyopathy" Abstract Gropler M., Lipshultz S.E., Wilkinson J.D., Towbin J.A., Colan S.D., Canter C.E., Lavine K.J., Simpson K.E.

Circulation
November 2020

"Impact of the COVID-19 Pandemic on Congenital Heart Disease Care and Emotional Wellbeing" Cousino M., Pasquali, S., Romano, J., Norris, M., Yu, S., Reichle, G., Lowery, R., Viers, S., Schumacher, K.

Cardiology in the Young
December 2020





TOP TO BOTTOM: Neha Bansal, M.D. Joseph Rossano, M.D.

STRENGTH IN RESEARCH

CCF continues its research **partnership** with the American Heart Association, American Academy of Pediatrics, North American Pediatric Cardiomyopathy Registry, and the Kyle John Rymiszewski Foundation to **accelerate research** on pediatric cardiomyopathy.



AMERICAN HEART ASSOCIATION

Melanie R. F. Gropler, M.D. of Washington
University School of Medicine in St. Louis,
Mo. was selected by the American Heart
Association Young Hearts Council as the 2020
Early Career Investigator for her CCF-funded
work on children with dilated cardiomyopathy.
This award recognizes young physicians
conducting high quality research on pediatric
cardiovascular disease.



KYLE JOHN RYMISZEWSKI FOUNDATION

Suzanne M. Mone, M.D., M.S. was awarded the Children's Cardiomyopathy Foundation and Kyle John Rymiszewski Foundation 2020 Research Scholarship to work on studies with the Pediatric Cardiomyopathy Registry. The scholarship offers a mentored fellowship that trains clinical researchers interested in studying hypertrophic cardiomyopathy in children.



STRENGTH IN EDUCATION

STRENGTH IN EDUCATION

Throughout the year, CCF **updated the medical community** on research publications, medical meetings, funding opportunities, and new family resources related to pediatric cardiomyopathy.

- 42 Cardiomyopathy Centers of Care in the U.S. and Canada were recognized during Children's Cardiomyopathy Awareness Month. These specialty centers were recognized for their highquality cardiac care and comprehensive approach to treating children with cardiomyopathy.
- Due to recommendations issued by the Centers for Disease Control on large gatherings, many live conferences were cancelled, postponed, or changed to virtual events. As a result, CCF limited its presence to **3 conferences** in 2020.

Parent Heart Watch

Pediatric Congenital Cardiovascular Disease Annual Update Rady Children's Hospital Annual Heart Party

 CCF's 5th International Conference in Children planned for April 30-May 1 in Washington D.C. was postponed to 2021 due to travel restrictions placed on medical professionals and health concerns associated with COVID.

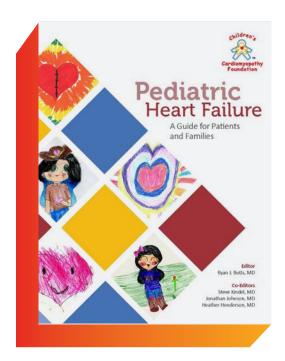




"Through CCF, I learned how important it is to find a cardiologist who specializes in pediatric cardiomyopathy. I also found the support system that I needed to help with the struggles of having a child with this disease."

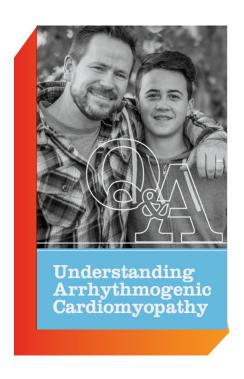
STRENGTH IN EDUCATION

CCF developed **two new educational resources** to meet the informational needs of more families.



PEDIATRIC HEART FAILURE GUIDEBOOK

Pediatric heart failure specialists from 13 medical centers across the U.S. and Australia collaborated with CCF to develop *Pediatric Heart Failure: A Guide for Patients and Families*. The comprehensive guidebook, funded in part by Novartis, serves as a companion piece to CCF's *Pediatric Heart Transplants: A Guide for Patients and Families*.



ARRHYTHMOGENIC CARDIOMYOPATHY INSERT

To complete the "Understanding Pediatric Cardiomyopathy" series of patient materials, an "Understanding Arrhythmogenic Cardiomyopathy" insert was developed with physician input. The new piece is being distributed to CCF's network of hospitals throughout the U.S.

"Not only did CCF provide us with support, but they offered a wealth of resources that made our journey easier.

Along the way, CCF's information gave us hope."



STRENGTH IN ADVOCACY

STRENGTH IN ADVOCACY

At the **Federal level**, CCF built relationships with key **Congressional leaders** to elevate pediatric cardiomyopathy on their legislative agenda. Support for cardiomyopathy legislation was overshadowed by congressional focus on larger issues such as the COVID outbreak, an economic recession, and a contentious impeachment and election process.

- SAFE PLAY Act during National Heart Month.

 During National Heart Month in February,

 CCF worked with Senator Robert Menendez

 (D-NJ) and Representative Bill Pascrell

 (NJ-09) to introduce the Supporting Athletes,

 Families and Educators to Protect the

 Lives of Athletic Youth (SAFE PLAY) Act.

 The bill includes important provisions that

 protect student athletes from sports-related

 medical emergencies such as sudden cardiac

 arrest, which is commonly associated with

 cardiomyopathy.
- CCF Takes the Lead in Supporting the Cardiomyopathy HEARTS Bill. CCF is taking an active role in supporting the bipartisan Cardiomyopathy HEARTS Act (H.R. 6166) introduced on March 10 by Reps. Andy Kim (NJ-03) and Andy Barr (KY-06). The Cardiomyopathy HEARTS Act calls for the establishment of surveillance research on cardiomyopathy across the lifespan and the development of educational materials targeted to school administrators, educators, and families.



"The cardiomyopathy
bills can save lives
and help families,
like mine, who have
been impacted
by the disease."

STRENGTH IN ADVOCACY

Department of Defense Peer Reviewed Medical Research Program. Due to CCF's advocacy efforts in Washington D.C., cardiomyopathy was included in the Department of Defense Peer Reviewed Medical Research Program for FY21, creating an additional source of federal funding for cardiomyopathy research studies. \$370 million will be directed to the Peer Reviewed Medical Research Program.





Sarah Foye of New Jersey was nominated by CCF to participate as a consumer advocate in the review of research applications submitted to the Department of Defense Congressionally Directed Peer Reviewed Medical Research Program. Foye, along with Melissa McQueen, Joseph Hillenburg, and Wendy Borsari—all CCF nominated parents—worked with prominent scientists to determine how research funds appropriated by Congress should be spent.



STRENGTH IN AWARENESS

STRENGTH IN AWARENESS

CCF joined the Global Heart Hub with other patient advocacy organizations from the U.S., Australia, Spain, Germany, Italy, and the Netherlands. The International Cardiomyopathy Council was formed to **develop an international campaign** in 2021 to raise awareness of the disease and encourage individuals to seek medical help where appropriate.



CCF focused on **raising awareness** of pediatric cardiomyopathy during National Heart Month in February and Children's Cardiomyopathy Awareness Month in September.





STRENGTH IN AWARENESS

NATIONAL HEART MONTH

#nationalheartmonth

- Over 500 people shared facts about cardiomyopathy, and nearly 9,000 people viewed CCF posts.
- Families and friends wore red, handed out CCF valentines, and distributed materials on cardiomyopathy.
- Letters were sent to congressional members in Washington D.C. in support of cardiomyopathy-related legislation.

- 8 Bake for a Cure events were hosted by CCF families in their communities.
- 235 guests celebrated National Heart Month at CCF's Night for a Cure event in New York City.





STRENGTH IN AWARENESS

CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH

#Knowyourheart

- 17 health and school national partners, along with CCF, urged families to learn the signs, symptoms, and risk factors of cardiomyopathy.
- Hundreds of social media postings and newsletter articles educated the public on the importance of knowing one's family heart history.
- A webinar featuring Mike Papale from In a Heartbeat spoke about his personal experience of surviving a cardiac arrest and unexpectedly being diagnosed with cardiomyopathy as a teenager.



CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH PARTNERS



































In a year when **self-isolation** and **social distancing** was necessary, CCF emphasized **online connections** and reached out to more affected families worldwide.

- Welcomed 250 new members, increasing CCF's community to over 3,300 members from 78 countries
- CCF's Family Facebook Community Group grew to over 1,900 members, generating 650 posts and 7,000 comments annually
- CCF Connect, an online community, has grown to nearly 600 active members
- Responded to over 760 requests for information through phone and email



"While we were waiting for our son's new heart, we participated in CCF's online discussions and drew from CCF's educational resources so that we could become better informed. Having these resources proved to be invaluable."

CCF offered **opportunities for families** to become **more informed** on living with cardiomyopathy.

- Launched new mobile friendly website with updated copy and new reference sheets on genetic mutations and genetic testing.
- Developed new Hospital Care and Bereavement guidebooks.







• Scheduled 10 educational webinars featuring cardiomyopathy leaders in the field.

Updates in Medical Management in Pediatric Cardiomyopathy

Beth Kaufman, M.D. Lucile Packard Children's Hospital at Stanford

Q&A on Cardiac Electrophysiology

Robert Pass, M.D.

Mount Sinai Kravis Children's Hospital

COVID-19 and Pediatric Cardiomyopathy: Information and Updates

Daphne Hsu, M.D. & Margaret Aldrich, M.D. Children's Hospital of Montefiore

Financial Considerations: Top Things to Help with Transplant Finances

Rick Lofgren, M.B.A. Children's Organ Transplant Association Allison Pela Phoenix Children's Hospital

Educational Considerations for Your Child: IEP/504 Information For Every Transplant Family

Stacy Hillenburg, M.Ed. Right Start Pediatric Therapies

Emotional Considerations for Pediatric Cardiomyopathy Families During COVID 19 and Beyond

Debra Lefkowitz, Psy.D. Children's Hospital of Philadelphia COVID-19 Updates for Cardiomyopathy Families

Daphne Hsu, M.D. & Neha Bansal, M.D. Children's Hospital of Montefiore

Research Study Update: Psychological Stress in Pediatric Cardiac Patients and Caregivers During COVID-19

Melissa Cousino, Ph.D. & Kurt Schumacher, M.D., M.S. C.S. Mott Children's Hospital

Supporting Your Diagnosed Child: Suggestions from a Patient

Mike Papale In A Heartbeat

Updates in Genetic Testing Related to Pediatric Cardiomyopathy

Wendy Chung M.D., Ph.D. & Teresa Lee, M.D. New York Presbyterian Morgan Stanley Children's Hospital

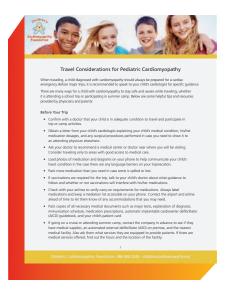
- Worked with CCF medical advisors to update the Understanding Pediatric Cardiomyopathy series of materials and increased offering of Spanish language materials.
- CCF collaborated with Transplant Families during National Pediatric Transplant week in April to offer two webinars geared towards pre- and post-transplant families.
- Developed 3 new fact sheets for the CCF
 Connect online community and updated CCF's
 Heart Camps Resource sheet to include 2020
 Virtual Heart Camps.

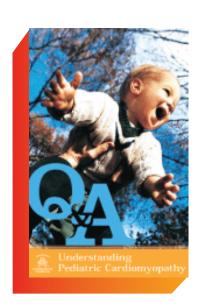
Emergency Identification Resources

Exercise & Sports Information Updates

Travel Considerations with Cardiomyopathy









FOCUS ON FUNDRAISING & FINANCIALS

FOCUS ON FUNDRAISING & FINANCIALS

CCF's Cure events bring families and supporters together to raise funds for CCF-directed research and education projects. CCF's fundraising events were severely impacted by prolonged restrictions on in-person gatherings.

Night for a Cure was CCF's last in-person event before nationwide lockdowns went into effect. From March, CCF pivoted to virtual events for the remainder of 2020.

2020 FUNDRAISERS



NIGHT FOR A CURE

More than 235 guests attended CCF's 12th Annual Night for a Cure on February 5. The event was held at the art decoinspired Edison Ballroom in New York City. The event raised more than \$240,000 for research and education initiatives.



WALK FOR A CURE

Walkers from around the country organized virtual walk teams during Children's Cardiomyopathy Awareness Month in September. More than \$16,000 was raised to sustain CCF's family resources and support services.



BAKE FOR A CURE

8 Bake for a Cure events took place during National Heart Month to raise community awareness and research funding for pediatric cardiomyopathy.

FOCUS ON FUNDRAISING & FINANCIALS

FAMILY FUNDRAISERS

Families got creative during the year planning more **outdoor** and **virtual events** to keep their community and network **engaged**.



SUPER HEART HEROES AUCTION



MOMMY & ME DAY



NEIGHBORHOOD YARD SALE

2020 FINANCIAL SUMMARY

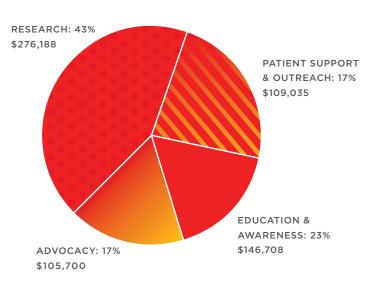
FISCAL YEAR ENDING DECEMBER 31, 2020

STATEMENT OF FINANCIAL POSITION		STATEMENT OF ACTIVITIES	
ASSETS		REVENUE	
Cash & Cash Equivalents	\$1,146,868	Contributions	\$332,466
Investments	\$1,440,182	Fundraising + Special Events	\$229,367
Intangible Net Assets	\$51,163	Net Investment Return	\$292,878
TOTAL ASSETS	\$2,638,213	TOTAL REVENUE	\$854,711
LIABILITIES + NET ASSETS		EXPENSES	
Accounts Payable & Accrued Expenses \$12,500		Programs & Services	\$637,631
Refundable Advance	\$77,114	Management & General	\$103,901
SBA EIDL Portion	\$100,000	Fundraising	\$187,019
Unrestricted Net Assets	\$2,349,918		
Restricted Net Assets	\$98,681	TOTAL EXPENSES	\$928,551
TOTAL LIABILITIES + NET ASSETS	\$2,683,213	NET INCOME	(\$73,840)

TOTAL EXPENSES

PROGRAMS & SERVICES: 69% \$637,631 FUNDRAISING: 20% \$187,019 MANAGEMENT & GENERAL: 11% \$103,901

EXPENSES BY PROGRAM & SERVICES



2020 TOP DONORS

We extend our **heartfelt thanks** to all who have contributed to the Children's Cardiomyopathy Foundation this year. The following corporations, foundations, and individuals have made significant contributions to the Foundation in 2020.

DONORS \$10,000 AND OVER

Amgen USA

Megan Cosby & EAC Foundation

Cytokinetics

MacKay Shields

Macquarie Group Foundation

Heather Riley

DONORS \$9,999-\$5,000

Dan & Stacie Allen

Bank of America Merrill Lynch

Cantor Fitzgerald Securities

Benji Cheung

Christopher DeLong

Lucas Detor

Goldman, Sachs & Co.

Carney & Melissa Hawks

Invitae Corporation

JP Morgan Chase & Co.

Kyle John Rymiszewski Foundation

Kathleen Lenihan

Geoffrey & Kearby Parker

Alexander Reiss

Ian Sandler

Adam Savarese

Senator Investment Group

Stifel Nicolaus & Company

TP ICAP

Wells Fargo Securities

DONORS \$4,999-\$1,000

Akin, Gump, Strauss, Hauer & Feld

Edward Almenara

Angel Island Capital Management

Angelo, Gordon & Co.

Barclays Capital

Evan & Beth Bernardi

Andrew Brenner

Justin Brody

Edward Burdick

William & Holly Caggiano

Nicholas Casesa

Christopher Chang

Won Choi

Citigroup Global Markets

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DeFeo Materials

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Gibson, Dunn & Crutcher

GLC Advisors & Co.

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Brian Hewitt

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HSBC Securities (USA)

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Owen Lipp

Kristin Lobron

Macquarie Capital

Mike & Kristi McCluskey

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Morgan Stanley

MUFG Securities Americas

Brian Mullins

Nomura Securities International

Brett Nunziata

Ronald Ory

Douglas Pardon

Israel Pollack

RBC Capital Markets

Rebeca Romero Rainey

Edward & Krista Renenger

Richards Kibbe & Orbe

Riva Ridge Capital Management

Donald & Mary Lou Rossi

RW Baird

Marc Schwartz

Scotiabank

Jason & Heidi Scribner

Scott & Sarah Snell

Robert Stobo

Michael Tama

Trumid Financial

UBS Investment Bank

Van der Linden Family Foundation

Matthew Williams

Andrew Wise

Eddie Yu & Lisa Yue

Dick & Maggie Yue

Raymond & Evelyn Yue

Richard Zentko

