



**Global
ARCH**

Global Alliance for Rheumatic
and Congenital Hearts



2022

Annual Report

MESSAGE FROM THE PRESIDENT



Dear friends,

This past year has been transformational for Global ARCH, continuing our growth from a small grass-roots organization into a recognized leader in global advocacy on behalf of those living with congenital and rheumatic heart disease. We continue to be the only organization in the world dedicated to empowering and uniting CHD and RHD patient and family organizations, and we ended 2022 with **57 member organizations from 32 countries**.

Thanks to our hard-working and committed volunteers, and a global community that is welcoming connection, throughout the year Global ARCH offered our members expanding opportunities to connect and learn, including a new **Advocacy Toolkit** designed to help organizations initiate in-country advocacy campaigns designed to meet critical needs in their community. We also engaged with the global CHD and RHD professional communities with our continuing webinar series, and our board represented the Global ARCH perspective at a number of professional conferences and on-line venues. Global ARCH also collaborated on several high-profile publications, including "Recommendations for "Developing Effective and Safe Pediatric and Congenital Disease Services in low- and middle-income countries: A Public Health Framework", published in *BMJ Global Health*.

Global ARCH continues to center its awareness campaigns around the **Declaration of Rights for Individuals with Childhood-onset Heart Disease**, which states that access to high-quality, life-long CHD and RHD care is a basic human right. Thanks to tremendous participation by our member organizations in our **Congenital Heart Disease Week** social media campaign, the number of signatures grew ten-fold in just under three weeks.

All the above activities, and many more, were made possible by the tremendous efforts of our global network of passionate volunteers and generous donors. Together, we are helping ensure that every person affected by childhood-onset heart disease thrives throughout the lifespan.

Thank you,
Amy

A handwritten signature in brown ink that reads "Amy Verstappen". The signature is fluid and cursive, with the first name "Amy" and last name "Verstappen" clearly legible.

Amy Verstappen, Global ARCH President



What is Global ARCH

Global ARCH is an alliance of congenital (CHD) and rheumatic heart (RHD) patient and family organizations from around the world. We have over 40 member organizations, representing 30 countries, with one-half from low-to-middle-income countries.

Our Mission

Our mission is to improve worldwide life-long outcomes in childhood-onset heart disease. We do this by empowering patient and family organizations from around the world to learn, collaborate, and speak out together about the unmet needs of those living with childhood-onset heart conditions.

What We Do

We connect and strengthen CHD and RHD organizations globally through peer mentorship, leadership development, educational resources, and regional and global conferences.

We speak out for the rights of CHD and RHD patients through our Rights Campaign and by promoting and supporting patient and family-led advocacy.

We educate patients, professionals, and humanitarian organizations on the global needs of CHD and RHD patients and the issues that matter most to our communities.

We collaborate with professional and humanitarian organizations to advocate for better services for every person affected by childhood-onset heart disease.



Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Fundación de Estrellita Belén

Each year about 1.3 million children are born with congenital heart disease (CHD)

WORLD
HEARTWAY

@estrellitadbelen
@globalarchorg

EMPOWERING OUR MEMBERS

Publications

We are continually adding to our **Resources** section. Some recent additions include:

Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association.

Healing Hearts and Minds. A Holistic Approach to Coping Well With Congenital Heart Disease by Tracy Livecchi and Liza Morton. Published by Oxford University Press.

WhatsApp

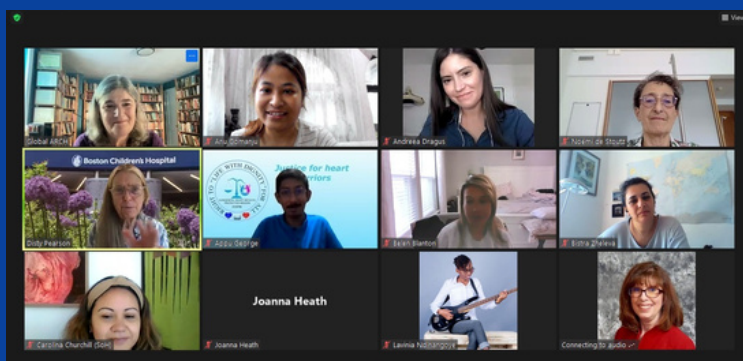
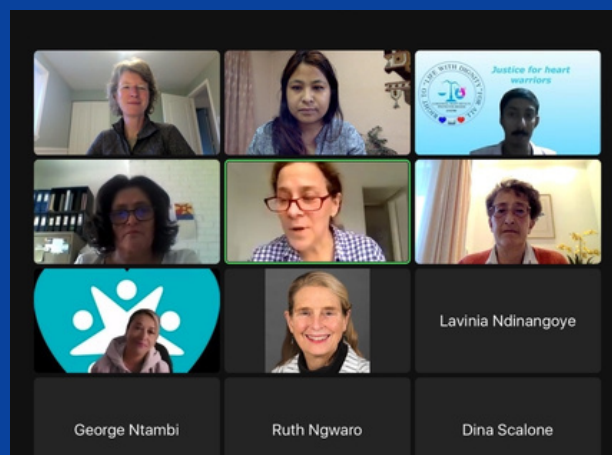
Another popular resource that is widely used among our members is WhatsApp, where members can post activities, ask questions, and share resources. It's an active message board open to all Global ARCH members. If you're a leader who would like to be added to our WhatsApp group please send us a message to info@global-arch.org.

Leaders' Forum



This year we hosted 11 Forums, and each meeting, held on Zoom the first Friday of the month, brings together a fresh combination of participants, all eager to share their experiences and learn from each other.

These Zoom meetings are a favourite amongst our leaders, because they offer an opportunity to meet casually, speak openly, and forge lasting support networks and friendships.



Declaration of Rights for Individuals with Childhood-Onset Heart Disease - Update

Global ARCH firmly believes that every person with childhood-onset heart disease deserves the right to health. In February we began the month with an existing 166 **Declaration of Rights** signatures, and had 1,273 by February 27! It was a very spirited (and competitive!) team effort and we all had a lot of fun rising to the challenge! A big shout-out to our leaders from Uganda, Venezuela, Malaysia, and the United States for topping the charts!

Thanks to our multilingual volunteers, the Declaration was translated into Italian, Malaysian (Bahasa), and Spanish. Thank you all for your efforts!



Networking Opportunities

The **World Heart Federation** created a new affiliate membership status for patient and family groups, and there was a lot of interest from our members. Global ARCH served as a connector organization, and is thrilled to support its members through the application process. This year, Belen Blanton and her organization Estrellita de Belen Foundation were accepted as members. Congratulations Belen!



SHARING OUR PERSPECTIVE

Webinars

Global ARCH LIVE: Promoting Well-being in CHD: A Global Perspective

This fantastic webinar featured **Dr. Laila Ladak**, associate professor and nurse scientist, The Aga Khan University in Pakistan, and **Dr. Adrienne Kovacs**, clinical psychologist and co-author of the AHA Statement on Mental Health Outcomes and Interventions for People with CHD. As well, **Dr. Liza Morton**, psychologist and CHD patient and co-author **Tracy Livecchi**, a social worker and CHD patient, discussed their new book *Healing Hearts & Minds*, published by Oxford University Press. Lastly, **Grace Jerald**, CHD patient and founder of CHD Malaysia, shared her patient perspective. This webinar was in partnership with the **International Society for Adult Congenital Heart Disease (ISACHD)**.

Heru Kustiwan, founder of **Little Heart Community** in Indonesia, hosted a very lively and interactive webinar "*Talk Show with ACHD*", featuring ACHD patients, including Amy Verstappen, Noemi de Stoutz, Apu K. George, and Peter Niewendyk.

GLOBAL ARCH LIVE: Promoting Well-being in CHD Patients: A Global Perspective



Dr. Adrienne Kovacs, AHA Statement on Mental Health Outcomes and Interventions for People With CHD



Dr. Laila Ladak, Assoc Prof and Nurse Scientist, The Aga Khan University, Pakistan, Global Health Chair, ISACHD



Dr. Liza Morton, psychologist and co-author of *Healing Hearts & Minds*



Tracy Livecchi, social worker and co-author of *Healing Hearts & Minds*

November 9 @ 10 AM EST
Please register:
<https://bit.ly/3DidKad>



Hosted by:



Loved ones and Healthcare Providers



Growing up with a sister with a CHD I didn't understand the seriousness of it all, it was just part of our life. The doctor's appointments, hospital stays, surgeries etc. She didn't look or act sick, so I honestly never thought of her as sick. As an adult and mother it hits me like a ton of bricks what she has endured and I am heartbroken for what she has gone through and continues to deal with. However, when I look at her now, I still don't see sickness: I see courage, strength, pride and have complete admiration, **Marie, 51, sister, US**

My wife has been through lots of medical crises which have impacted our family life. I have always tried to stay calm for her while focusing on keeping things as normal as possible for our son, **Jamie, 45, husband, UK**



It takes a lot for many of our patients to trust us, given their understandable anxiety and sometimes poor previous experiences with healthcare. It's a real challenge to maintain communication through that, to demonstrate a commitment to working through that as a patient/healthcare team, and nothing is more rewarding than a patient learning to trust you, **ACHD Cardiologist, UK**

Anxiety & depression in pediatric CHD



Pooled prevalence from meta-analysis of 16 studies:

Internalizing behaviour difficulties (eg, depression, anxiety): 25%

Externalizing behaviour difficulties (eg, defiance, oppositional): 15%

Lifetime prevalence of psychiatric disorder may be as high as 65% among adolescents with single ventricle CHD



Abida et al, J Ped Psychol, 2019;
DeMaso et al, Pediatrics, 2017

'Dual-expert' co-authors

- **Liza:** Counselling Psychologist, PhD, Psychology Lecturer & Researcher, Management Board, Somerville Heart Foundation, led successful campaign for CHD healthcare standards in UK. Fitted with 1st cardiac pacemaker at 11 days old in 1978; world first at the time, ASD, dependent on pioneering medical treatment & countless interventions since.
- **Tracy:** Clinical Social Worker working in Connecticut, Mental Health Consultant to the ACHA's Peer Mentorship Program, born with a complicated CHD requiring several surgeries & hospitalizations.
- Met online through advocacy efforts, felt lack of support for psychological & emotional impact, the book that we have been looking for yet could not find.







Talk Show with ACHD
(Presented by Little Heart Community)

Amy Verstappen
PENYINTAS CCTGA

"Let your children decide by themselves who they want to tell about their condition"





Talk Show with ACHD
(Presented by Little Heart Community)

Apu K. George
PENYINTAS DEXTROCARDIA WITH PULMONAL & TRICUSPID ATRESIA

"Surgery makes a drastic change into my life"

Presentations

Amy Verstappen spoke about patient and family advocacy at the American College of Cardiology, with **Disty Pearson** co-chairing the session. She discussed the **impact that Global ARCH member organizations are making in their communities, opportunities available to them, and some of the work of Global ARCH.**

In April, **Bistra Zheleva** and **Tendai Moyo** attended the **WHO consultation with people living with non-communicable diseases (NCDs)**, and reported that it was a great experience. Specifically, Tendai said *"I believe we have played our part the best way we could for heart disease communities and NCDs in Zimbabwe."* Some of their work included initiating the Noncommunicable Disease Alliance in Zimbabwe, pioneering the first cardiac unit in Southern Region in the country, and helping to initiate the neurosurgeon ward renovations for the Hydrocephalus Association, based at Mpilo. They achieved these measures by encouraging NCD partners to rise up and let their voices be heard.

Anu Gomanju attended the **World Heart Summit** in Geneva to share her personal experiences with RHD to inform the broader context of advocacy and awareness raising around cardiovascular health. *"I will be representing Global ARCH, NCDI Poverty Network and its Nepal office, to share my lived experiences in this virtual Global summit."* At the World Heart Summit, Anu was interviewed by **Dr. Liesl Zuhlke** on the patient experience of having RHD.

Anu was also featured in **Nothing For Us, Without Us**, new film series on people living with noncommunicable diseases and mental health conditions, available on the WHO's YouTube channel.



Publications

Shelagh Ross was invited to contribute a patient perspective article *“Aging with congenital heart disease: are we satisfied with life or simply enjoying ‘low-bar syndrome’?”* published in the December issue of the *European Journal of Cardiovascular Nursing*.

Tendai Moyo, founder of **Brave Little Hearts Zimbabwe (BLHZ)**, was featured in *The Sunday News*. Here is just one quote: *“As the Ministry of Health and Child Care, we are grateful to Brave Little Hearts for bringing to the fore the plight of children born and living with congenital heart diseases. So although we are aware that there are children born with the disease, as we plan and advocate for resources in hospitals we will not forget that population.”*

Global ARCH members were invited to contribute their personal experiences living with CHD for inclusion in **Liza Morton** and **Tracey Livecchi**’s book *Healing Hearts and Minds: A holistic approach to coping well with congenital heart disease*, published by Oxford University Press. The book features diverse perspectives from people living with CHD, and coping mechanisms for living well with CHD.

Anu Gomanju was also featured in the **RHD Pulse newsletter** patient spotlight section, and is quoted, *“People with lived experience are invaluable to helping understand barriers and identify solutions to treatments, programmes and policies and to also aid in the design of sustainable interventions. It is crucial because our voices and experiences can be one of the resources which the stakeholders are saying they are lacking in achieving the global target set on NCDs, including RHD. Therefore, it is important that people living with RHD are meaningfully engaged in the co-design, co-production or the implementation of related health services, programmes, or policies – ultimately the things that matter most to us.”*



European Journal of Cardiovascular Nursing (2022) 00, 1
European Society of Cardiology <https://doi.org/10.1093/ejcn/znac110>



Aging with congenital heart disease: are we satisfied with life or simply enjoying ‘low-bar syndrome’?

Shelagh Ross*

Global Alliance for Rheumatic & Congenital Hearts (Global ARCH), Victoria, BC, Canada



Anu Gomanju, RHD patient and advocate based in Nepal.

Healing Hearts and Minds

A Holistic Approach to Coping Well
With Congenital Heart Disease

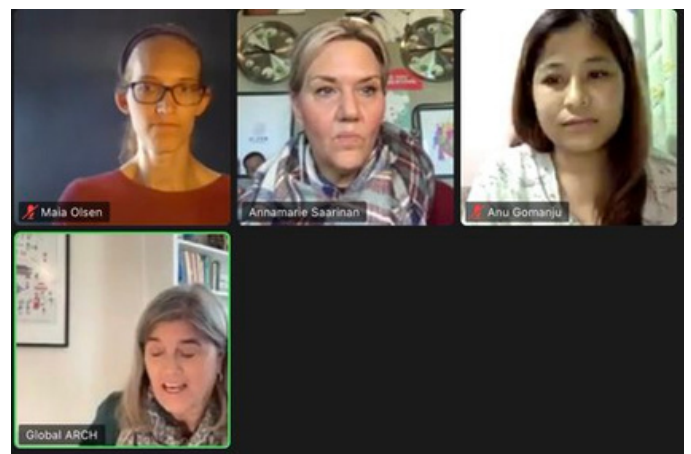
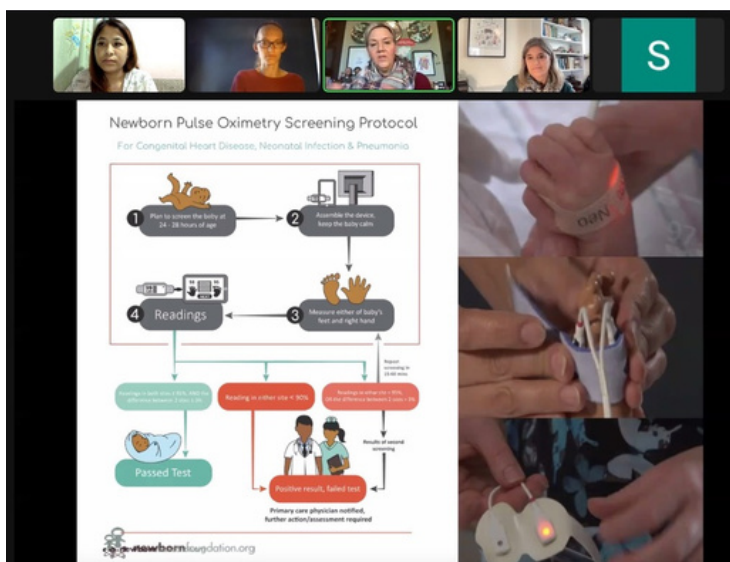


Tracy Livecchi, LCSW Liza Morton, PhD

A photograph of a woman with dark hair, wearing a purple patterned top, smiling broadly while holding a baby. The baby is wearing a white sleeveless shirt and a white sock on one foot. In the background, a cartoon character resembling Mickey Mouse is visible on a wall. The image is used as a background for the 'advocacy toolkit' cover.

Our Advocacy Toolkit, developed in partnership with Children's HeartLink, was created to help patient and family groups, non-governmental organizations, professional societies/organizations, and individuals achieve their advocacy goals. It starts by **defining advocacy** and providing insight into **identifying the issues**, complete with **patient rights and key facts about childhood-onset heart disease**. It covers **how to define advocacy goals**, with concrete examples, and demonstrates **how to identify the target audiences**. Finally, it discusses **how to make an advocacy plan, develop key messages to help put ideas into action, and measure success**. The Advocacy Toolkit is a wealth of information, developed by people who have been tremendously successful in the area of childhood heart disease advocacy.

Global ARCH LIVE webinar **Advocating from the Heart**, in partnership with the **NCDI Poverty Network**, focussed on how patient and family leaders can initiate and sustain government-directed health advocacy. **Maia Olsen**, Advocacy Director of the NCDI Poverty Network, gave an overview of activities that led from the WHO's adoption of the RHD resolution to regional efforts around the PEN-Plus strategy. **Annamarie Saarinan**, CEO of the Newborn Foundation, described the successful campaign to achieve universal pulse oximetry screening the United States, and **Anu Gomanju**, NCDI Poverty Network Advocacy Fellow, talked about their activities in Nepal.



Research

Global ARCH participated in writing an article entitled *Recommendations for Developing Effective and Safe Pediatric and Congenital Heart Disease Services in Low- and Middle-Income Countries: A Public Health Framework*, to be published in BMJ Global Health.

Global ARCH and REACH partnered to create an informal survey for patients and families on the impact of COVID on their health and well-being. It is an attempt to gain more detailed information on COVID's impact globally, with a special interest in low- and middle-income countries.

BUILDING OUR SUSTAINABILITY

New Strategic Plan

In early 2022 we focussed our energies on reviewing and updating our Strategic Plan ([link](#)), to ensure we were aligned with our mission and vision. We held a series of meetings – individually and as a board – to discuss our work to date and where we want to be in the coming years. Five objectives were developed, as follows, along with metrics:

Strategic Plan

1. Build organizational capacity to ensure long-term sustainability.
2. Strengthen and connect patient and family organizations to promote local and regional action.
3. Create and share information, resources and knowledge to empower the CHD/RHD community.
4. Build a global voice advocating for CHD and RHD rights in the global health agenda.
5. Unify and amplify the global voice of the CHD/RHD community to inform, educate and promote action.

In 2022 we saw a welcome growth in revenue, accentuated by a generous anonymous donation, aptly named “The Coherence Fund”, which will be used to focus on life-long care. We feel confident that we will be able to fulfil our goals and continue to improve worldwide life-long outcomes in childhood-onset heart disease through empowering patient and family organizations worldwide.

Global ARCH Members

Adult Congenital Heart Association
Adultos con cardiopatías congénitas de Argentina
Action for Disadvantaged People
AICCA Onlus
Amar El Club De Los Corazones Peculiares
Amigos de Corazón
Brave Heart
Brave Little Hearts Namibia
Brave Little Hearts South Africa
Brave Little Hearts Zimbabwe
Bundesverband Jemah E.V.
Camp Odayin
CHD Malaysia
Child Heart Care Project under National Institute
for Woman and Child Development
Children's Heart Association
Children's HeartLink
Children's Heart Federation
Congenital Heart Disease India
Connecting Hearts to End Heartbreak (CHEER
Hearts)
Conquering CHD
Cuore Matto
Cure Kids Fiji
European Congenital Heart Disease Organization
Finnish Association for Heart Children and Adults
Fundacion Estrellita de Belen Corp
Fundación Menudos Corazones
Global Cardiac Surgery
God-Reign Gospel Productions
Heart and Stroke Foundation

Heart Kids Ltd.
Heart Kids New Zealand
Heart Kids South Africa
Heart Warriors of the Philippines Inc.
Hearts Unite the Globe
Herznetz.Ch
Hjärtebarnsfonden
International Society for Adult Congenital Heart
Disease
Jemah Ev
JK HOPE & HEALTH FOUNDATION
Justice For Heart Warriors
Kardias AC
Kehilat HaLev (The Heart Community)
Kenya Mended Hearts Patient Association
Let it Echo
Little Heart Community
Mending Tiny Hearts
Pakistan Children's Heart Foundation
Pan African Network of Pediatric and Congenital
Hearts
PANHELLENIC CONGENITAL HEART DISEASE
ASSOCIATION
RHD Support Group, Uganda Heart Institute
Surgeons of Hope
Sydänlapset Ja -Aikuiset Ry - Finnish Association
Team Heart Inc
The Mended Hearts, Inc.
The Children's Cardiac Foundation of Africa
Voice of a Heart/Ijwi ry'Umutima
William Novick Global Cardiac Alliance

Board of Directors

Amy Verstappen - President
Disty Pearson - Vice-President
Shelagh Ross - Secretary
David La Fontaine - Treasurer
Farhan Ahmad
Flavia Kamalemba Baturine
Vikas Desai
Noemi de Stoutz
Grace Jerald
Mehwish Mukhtar
Lavinia Ndemutla Ndinangoye
Ruth Ngwaro
Dominique Vervoort
Bistra Zheleva

Medical Advisory Board

Kathy Jenkins, MD, MPH
Disty Pearson – Board Liaison and Vice-Chair
Christopher Hugo Hamman, MD
Bbar S. Hasan, MD
RK Kumar, MD
Sivakumar Sivalingam, MD
Liesl Zühlke, MBChB, DCH, FCPaeds,
Cert Card, MPH, FESC, FACC, PhD

Welcoming new members

We are thrilled that our total membership increased exponentially to over 70 members this past year, with 34 family and patient organizations. Of course it's not really about the numbers, but about the amazing work these people are doing in their communities. Often with very few resources, they work tirelessly to improve the understanding RHD and CHD, convincing governments and other stakeholders to play a vital role. We salute our members for their hard, exhausting work, often under very difficult conditions.

As welcomed four new board members this year – **Belen Blanton Altuve**, a CHD patient and founder of **Fundacion Estrellita de Belen**, a very active non-profit that provides cardiac care to low-income children in Venezuela. **Anu Gomanju**, in Nepal, is currently a “Voices of NCDI Poverty Advocacy Fellow” with the NCDI Poverty Network, representing the RHD community. Anu also founded **Connecting Hearts to End Heartbreak (CHEER Hearts)**, a patient support and advocacy group in Nepal. **Tendai Moyo** became a fierce advocate for CHD patients after she lost her baby daughter to the disease. Since joining Global ARCH for support and inspiration, she has founded **Brave Little Heart Zimbabwe**, an active advocacy organization.

Inaugural Emeritus Member

Dr. Vikas Desai, one of our founding members, has moved from active board work to Emeritus status, to focus on the clinical demands that the COVID pandemic has created. We thank her for her support, enthusiasm, and valuable contributions to Global ARCH.

Saying goodbye to a cherished friend and colleague

The Global ARCH community was devastated to learn about the death of one of our founding members – **Noemi de Stoutz** – who has given so much of her time, energy, expertise, and wisdom, to help guide our efforts. Noemi was also very involved with Cuore Matto, a Swiss CHD organization that she supported for many years. As an oncologist by profession, Noemi developed the first palliative program for cancer patients. An expert in her field, and someone living with heart failure as a result of complex congenital heart disease, Noemi died peacefully.



A favourite photo from the archives, of Noemi collecting milk from her cow at her home in Switzerland.

Our Financial Health

as of December 31, 2022



■ Administrative Expenses
■ Program Expenses

Assets \$73,638

Cash \$73,638

Liabilities \$0

Equity \$73,638

**Total Liabilities
& Equity \$73,638**

Revenue

Grants \$3,000

Donations \$31,219

Total Revenue \$34,219

Total Administrative \$9,649

Total Program \$17,874

Total Expenditures \$27,523

Net Revenue \$6,696

Our Donors

Susan Fernandes
Vicki Gold
Annie Taylor Gray
Green Street Monthly Meeting
Jonathan Gutoff
Karen Keuhl
Ralph Kleinman
Tracy Livecchi
Paula Millet
Elizabeth Minott

Dorothy Pearson
Shelagh Ross
Dina Scalone
Carolyn Schiff
Patricia Taylor
Boroff & Maria Veneziano
Amy Verstappen
Jonathan Vogel
Marjorie Waters
Leah Whittington