# listening. learning. evolving.





ANNUAL REPORT | APRIL 2022 - MARCH 2023





As we come to an end of FY23, Autism Speaks is setting a course focused on the unique needs of each person with autism.

Together, we will build a path forward and drive change for a brighter future for all.

- Ensure access to reliable information and services across the lifespan
- Support research and innovation that drives towards improved quality of life and well-being for individuals with autism throughout their lives
- Leverage our assets through advocacy, partnerships, and collaboration to support, extend and convene the work of service providers
- Accelerate delivery of solutions for adult quality of life needs, including transition, employment, housing and health and wellness
- Live and promote principles of diversity, equity, access and inclusion both in and outside the organization





## Dear friends and colleagues,

Autism Speaks remains committed to a clear vision: working alongside the autism community to create an inclusive world in which all people with autism can reach their full potential. Our vision of the future fuels and guides our organization every day. It's a vision that we are dedicated to creating for generations to come.

This annual report represents a truly pivotal period. It shares our impact on the lives of autistic people and their families over the past year and is a springboard for an evolution. An evolution in the way we represent each person's experience with autism and Autism Speaks moving forward. In preparation for the final three years of our Next10Vision, we engaged in extensive conversations with hundreds of self-advocates, providers, families and supporters to ensure our work is informed by those who benefit the most. The result is a three-year strategic path that will have the largest impact on our community and address the areas of greatest need.

Early diagnosis and timely interventions will always play a key role in our work to improve lifelong outcomes. Our online screening tool continues to be the first step for many parents concerned about their child's development to learn the signs of autism and seek help. This year alone the survey was completed by nearly 342,000 families, surpassing 1 million total since 2020.

In the following pages, you will also see a focus on accelerating the delivery of reliable information, resources and solutions to the autism community, to driving change through partnerships and collaboration, to eliminating barriers to care and address significant gaps in services and supports for young and older adults and for those affected by severe and challenging behaviors - all with the goal of creating a more inclusive world.

Our advocacy efforts to improve health insurance coverage enables people with autism to face less denials, have increased access to care and benefit from cost savings of coverage. The launch of our first-of-its-kind interactive dashboard, *Autism by the Numbers*, has the potential to transform the way we understand and meet the needs of the autistic community; a new adult tool kit, created by autistic adults, addresses a significant resource gap for those diagnosed later in life. We continue to grow employment, education and other opportunities for autistic adults. The release of a clinical guide for treating severe behaviors in autism underscores our efforts to mitigate another critical gap in health equity. Integrated into all that we do, both externally and as an organization, is our dedication to diversity and inclusivity.

It is on us, as Autism Speaks and as the broader community, to make sure that we stand together for a world of difference. We know that we are not alone and are grateful for the enduring dedication of our supporters, volunteers and staff. We are excited about the future as we continue to **listen, learn and evolve.** 

With deep appreciation,

**Keith Wargo** *President & CEO* 

**Brian Harper** *Chairman, Board of Directors* 

# Ensuring access to reliable information and services





# Fostering a world in which all people with autism can reach their full potential.

It is this vision that drives the work we do each day. Our vigilance as a trusted and credible source is transforming the landscape of reliable information and opportunities for the autism community at every stage of life and level of support.

#### **Created a supportive community of belonging for our 2.8 million social followers** to make connections, obtain support, share knowledge and nurture understanding and inclusion.

In 2023, we shared over 400 stories, podcasts and open conversations around lived experiences of strength and challenge, access to resources and inclusive events. We learn from each other.

#### Viewed by over 818,000 visitors this year alone, our online resource directory is the largest autism provider database in the nation.

Targeted by location and vetted to ensure best practices and cultural competence, the directory enables individuals and families to gain access to autism resources when and where they need them.

#### **Responded to more than 76,500 phone calls, emails and chats** *from people with autism, caregivers and providers in need of answers and resources.*



To date, our Autism Response Team has made nearly 700,000 connections for people in need.

#### Hosted 59 free online educational events and webinars, attended by 20,400 stakeholders.

Provided applicable information and resources around autism and employment, early diagnosis and intervention, school community, transition, adulting, inclusion and service provider connections.

#### In collaboration with the World Health Organization and UNICEF, Autism Speaks funded the largest review of autism prevalence literature since 2012.

The findings indicated an increase in the global prevalence of autism, from 62 in 10,000 to 100 in 10,000 (1 in 100) children around the world. Supported by global evidence, the findings will be significant in aiding many countries and communities around the world that lack prevalence data to validate their need for increased autism tools and programs.

## Improving quality of life through research and innovation





Committed to accelerating research innovation and service delivery for faster, positive impact on the lives of autistic people.

The issues facing the autism community are more urgent than ever and motivate us to further address the areas of greatest need to improve quality of care and well-being.

# Launched "Autism by the Numbers," the first online nationwide dashboard of its kind.

Informed by autistic individuals, families, advocates and policymakers, the dashboard provides a better understanding of what autism services look like across the U.S. This hub of reliable data offers insight into the strengths and weaknesses of current systems, fuels advocacy efforts to drive change and enables autistic individuals and families to make more meaningful life decisions.

#### nationalautismdatacenter.org/autism-by-the-numbers



Partnered with Hospital for Sick Children (SickKids) on the world's most comprehensive study of how DNA architecture contributes to autism.

The study revealed 134-autism linked genes and associated changes leading to better diagnostics and ability to target and develop strategies for personalized care. \$720,000 in grant funding was provided to best-in-class, next-generation autism researchers helping to ensure a vital pipeline of new minds and ideas for the future of autism study.

These promising scientists' work will focus on solutions to address speech, motor delays, sensory challenges and loneliness in autistic adults.

#### **Released the first of its kind Clinician Guide:** *Program Development and Best Practices for Treating Severe Behaviors in Autism as a result of the 2020 Autism Speaks Thought Leadership Summit on Challenging Behaviors.*

The comprehensive guide, created by multidisciplinary autism leaders and researchers, addresses assessment, treatment, staff training, business model development and public policy priorities for autistic people with challenging behaviors.

## Leveraging our collective strengths to propel change





# Through advocacy, partnership and collaboration, we forge policies, foster innovation and transform lives.

We leverage our assets and join forces with the autism community to convene with others and advocate for change.

#### Successfully lobbied for the historic expansion of the Autism and Developmental Disabilities Monitoring (ADDM) Network from 11 to 16 sites.

This distinctive collaborative network tracks the number and characteristics of children with autism spectrum disorder (ASD) and other developmental disabilities. The increased data and knowledge will inform and assist us in identifying gaps in diagnosis, improving screening tools and developing programs to reach underserved communities.

#### United with 102 self-advocates and caregivers from over 20 states and D.C. at the 4th Autism Speaks Advocacy Forum and Hill Day in Washington, D.C.

Advocates held 104 congressional staff meetings, providing a powerful voice to secure support for federal autism funding. Year-round advocates conducted more than 340 meetings with congressional representatives on autism legislative priorities.



# Advocated for the successful passage of more than \$400 million in federal funding for autism research.

Autism Speaks maintains a constant, vigilant presence in support of yearly funding in diverse areas, including life span needs, heath equity, aging, mental health, transition and more, to meet the needs of the autism community.

#### Championed the enactment of Maryland's "End the Wait Act," reducing the wait list for the state's Autism Medicaid Waiver by 50 percent by FY24.

With a current waiting list of 8 to 9 years, this law will expand access to a vital array of supports like day programs and residential services.

#### **Contributed to the passage of new state legislation and regulatory policy** *for improved public and private health insurance coverage of medically necessary care.*

The wins in Iowa, Virginia, Georgia, Illinois, Florida, New York and Oklahoma will impact the lives of hundreds of thousands of autistic people through improved access to mental health treatment and therapeutic services, as well as improve provider network adequacy.



Improving quality of life





### We believe that all people with autism should lead fulfilling lives.

By eliminating inequities and improving access to quality care for autistic people, we are positively impacting their lives and those of their families.

#### Drove awareness to a severely understudied area by hosting the Thought Leadership Summit on Autism and Aging.

By bringing together self-advocates, families, researchers and policymakers we were able to discuss the biggest challenges facing autistic adults as they age and the next steps needed to support the community. Attendees unanimously supported the creation of a multi-disciplinary consortium to accelerate systems change to impact the lives of older adults on the spectrum.

#### **Engaged parents and caregivers viewed our free "quick caregiver tips" video series** *more than 15,600 times to help their autistic child engage in activities, expand their communication, learn new skills and more.*

In continued collaboration with the World Health Organization, we implemented five new Caregiver Skills Training sites in the U.S. and globally, enabling parents to build their child's developmental skills at home. Through these efforts, underserved communities are gaining greater access to quality care and interventions around the world. Nearly 342,000 parents concerned about their child's development accessed M-CHAT-R, a recognized autism screening questionnaire through the Autism Speaks website – taking the first step to learn the signs of autism and take action.

Over the past three years alone, more than 1 million families have completed the survey to ensure the best outcomes for their children.

#### Accredited the first state agency in the country with Autism Speaks Autism Friendly Designation.

Over 85 percent of Iowa Vocational Rehabilitation Services employees in 13 area vocational rehabilitation offices across the state completed special training to better serve and meet the needs of Iowans with autism. Step by step, state by state, we will work to improve the quality of life for all people with autism.



## Delivering solutions for adult needs



# Working together, we are accelerating a path forward for the lifelong well-being of autistic adults.

While early diagnosis, remains a key foundational focus of our mission work, we are committed to expanding our understanding of the challenges facing autistic adults. This includes informing clinical care, securing greater government investment in research and services and providing resources and tools to support an aging population.

#### **Created by autistic adults, the Autism Speaks 'Adult Diagnosis Tool Kit' provides a guide** to identify autism in adults and determine next steps.

The tool kit addresses a significant resource gap for those diagnosed later in life and amplifies what living on the spectrum looks like from the voices of autistic adults who have walked that path.



Nearly 8,200 autistic job seekers, employers and service providers took advantage of Autism Speaks employment events and Workplace Inclusion Now™ course access.

These educational events and courses highlight the value of a diverse workforce, raise awareness around differences in thinking and communication styles and provide strategies to build inclusive workplaces.

Increased job placements, access to critical transportation and community services, supportive peer connections and interview development as the result of a new Community Navigation Program.

The pilot program provided multiple personalized support sessions from members of our Autism Response Team to autistic adults around their employment needs.





### We continue to sharpen our focus on diversity, equity, access and inclusion for our community and ourselves.

Eliminating barriers and creating a culture of inclusion and connection is embedded in every aspect of our programs and purpose.

#### Introduced Hablemos Autismo, a new podcast for the Hispanic community around autism.

This broadcast, hosted by a member of the Autism Speaks Autism Response Team, helps raise awareness and address topics impacting the Spanish-speaking autism community and shares the voices and views of self-advocates, parents, professionals and more.

#### Hosted our first online Spanish-speaking educational event around early intervention and support.

More than 450 parents, caregivers, and service providers received critical resources and guidance on a child's most critical stage of development. Autism Speaks is committed to addressing disparities in autism diagnosis and treatments in underserved communities.

### **Caminos a la Intervención** Temprana y el apoyo en la comunidad latina

#### **11 DE OCTUBRE DE 2022** DE 12:00 p. m. A 2:30 p. m. (EST) **EVENTO VIRTUAL**



Escuche a expertos en autismo, profesionales médicos y padres de familia hablar de cómo reducir las barreras a la autism atención y el acceso a recursos de mejores speaks prácticas y apoyos.

Evento gratuito. Se requiere registro. Confirme su asistencia ahora.

Funded the education of 10,000 caregivers and health professionals across 55 countries on autism best practices in managing, maintaining, and coordinating care for a family member with autism.

The virtual training is provided through the Autism Care Network Family ECHO Autism programs and will enable improved access to care in underserved communities. Training includes managing symptoms related to anxiety, ADHD, irritability, family support, and how to support adolescents as they transition into adulthood.

#### **Expanded Autism Speaks Employee Resource Groups promoting a culture** of inclusion and belonging in the workplace.

Staff-led support groups around autism, race and gender-identity provide team members with a voice and visibility, create a sense of community and drive change toward a more equitable workplace.

## Powered by potential





# A commitment powered by the potential they see in themselves, of those that love and believe in them and those who help them achieve it.

The Autism Speaks Walk remains the world's largest autism fundraising event dedicated to improving the lives of people with autism. Individuals, their families, friends and providers came together in a network of friendship and support in 47 cities across the nation, raising more than \$6.6 million to ensure people with autism can reach their fullest potential.

### **Top Teams**

(Pittsburgh Walk)

<b>Team Katz</b> (Los Angeles Walk)	\$260,348	Team Aetna\$ 40,278(Connecticut Walk)
Team Topping / CNB (Los Angeles Walk)	\$101,411	Will Clark\$ 39,456(San Francisco & North Bay Walk)
<b>New York City Department of Sanitation</b> (New York City Walk)	\$ 76,003	Team Ingram\$ 37,287(Columbus Walk)
<b>Ryan Arenson</b> (Downtown Chicago Walk)	\$ 69,739	Mileti's Marchers\$ 34,836(Columbus Walk)
<b>Chicago Trading Company</b> (Downtown Chicago Walk)	\$ 58,369	Team Jessica\$ 27,477(Central Florida Walk)
<b>Jack Garchik's Crew</b> (Palm Beach Walk)	\$ 57,201	Ryan's Rappers\$ 26,079(St. Louis Walk)
<b>Christian's Crusaders</b> (Palm Beach Walk)	\$ 51,135	Teamsters Local 25\$ 25,463(Greater Boston Walk)
<b>Team CG &amp; Friends</b> (Los Angeles Walk)	\$ 41,923	Ante4autism4michael\$ 25,368(Columbus Walk)
PITT OHIO For Autism Speaks	\$ 41,800	

## Funding our mission





## With the help of our impassioned supporters, dedicated staff and amazing community, we're committed as ever to creating a world

where all people with autism have the opportunities, resources and support they need to live their best lives. We cannot understate the profound impact of their gifts.

#### Raising more than \$4.8 million, our wide range of fundraising events continued to rally our communities nationwide.

From spectacular galas and memorable gourmet cuisine to prestigious golf fundraisers, each event provided the critical funding to further our mission work.

# Whether racing as a professional or just for fun, our TeamUp event athletes ran with their heart.

With 10 national endurance events and five regional community runs, these fast-paced events raised more than \$1.4 million to fuel our mission.

#### Our newly launched Women Leading the Way program celebrated the strength and tenacity of women as leaders and changemakers for the autism community.

The inaugural event raised more than \$128,000. The overwhelmingly positive feedback inspired our decision to recreate the event throughout the country to showcase the vital role women play in making a world of difference for people with autism.

# We are energized every day by the unfaltering support of our individual donors *and their generous giving.*

In FY23, digital and mail donations generated \$7.9 million to help ensure all people with autism live their best lives.

Philanthropic gifts and grants from individuals, families and public/private foundations of nearly \$6.2 million advance the strategic priorities of Autism Speaks around improving equity and lifelong outcomes; amplifying autistic voices and the needs of those living on the spectrum; and accelerating and delivering solutions to enhance quality of life.

Their support makes possible our work in adulthood, employment, science and big data, clinical care and direct assistance.



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### Annually, the incredible generosity of corporate supporters and their dedicated employees drives Autism Speaks

to provide crucial autism research, advocacy, services and support to help people with autism and those who support them thrive. We deeply value their continued contributions and commitment to the autism community and our mission.



## In partnership and collaboration

1.800 12





# Autism Speaks Canada has continued to collaborate and address the needs of the autism community across Canada.

Our shared vision is creating a world where autistic people can reach their full potential.

#### **Created a three-part documentary series,** *Life on the Spectrum, to share the lived* **experiences of autistic Canadians** *and their families, coast to coast to coast.*

Autistic representation was part of every stage of development and dissemination. This free, innovative multimedia storytelling initiative is driving social change through education and increased understanding about autism and the autistic community at every level. The three episodes received a 93-97.7 percent positive likability rating with over 483,000 website views and nearly three million responses on social.

#### Joined the Digital Technology Supercluster and the Autism Sharing Initiative (ASI) funded by the Government of Canada and led by DNAstack.

The goal of the ASI is to facilitate sharing of consented healthcare data between researchers while preserving their individual data privacy. Breaking down information-sharing barriers that have traditionally prevented groups from unlocking the full potential of data, will enable us to accelerate research and speed the path to personalized care.

#### Continue an unwavering commitment to fostering inclusion, diversity, equity and accessibility (IDEA) within our organization.

This commitment is exemplified through the establishment of an internal committee focused on four pivotal areas: recruitment, career development, employee support and community programs. We prioritize self-advocate representation in our workforce boasting a team of four autistic board members, an all-autistic call center, autistic contractors, ambassadors, speakers, volunteers and staff.

# Advocating for a National Autism Strategy remains a top priority.

In 2022, the Canadian Academy of Health Sciences released an assessment report on autism funded by the Public Health Agency of Canada. We supported these efforts through a stakeholder engagement process including autistic people, advocates, Indigenous partners, families and caregivers, provinces and territories. The report is intended to inform the federal government as it considers the development of a National Autism Strategy.







#### APRIL 2022 - MARCH 2023

### **Funding Sources**

Total	\$ 73.9 M
Events	\$ 6.5 M
Walk Program/Corporate Partners	\$ 13.4 M
Major Gifts, Grants and Other Contributions	\$ 19.1 M
Donated and In-kind Goods and Services	\$ 34.9 M



Your Dollars at Work PROGRAM SERVICES			4% 10% Mgnt. and General Fundraising
Understanding and Acceptance		\$ 41.4 M	
Services and Support		\$ 14.7 M	
Science		\$ 14.5 M	18% 50%
	Total	\$ 70.6 M	Science Understanding
SUPPORTING SERVICES			and Acceptance
Fundraising		\$ 8.0 M	18% Services and
Management and General		\$ 3.3 M	Supports
	Total	\$ 11.3 M	

#### **Net Assets**

#### TOTAL NET ASSETS

at March 31, 2023

Total \$41.8 M

To view Autism Speaks' complete audited financial statements please refer to our website *autismspeaks.org/about-us/annual-reports*.

Included in the Funding Sources and *Your Dollars at Work* are donated and in-kind goods and services totaling \$34.9M, primarily related to media and related services.



## Board of Directors as of June 30, 2023

We are grateful to have such a dedicated and accomplished board and leadership team whose wide range of expertise and impassioned commitment is transforming the systems and standards of autism care and support.

#### Co-Founders

Bob and Suzanne\* Wright

Brian L. Harper, Chair Adrian M. Jones, Vice-Chair Jacquelyn "Jakki" Nance, Vice-Chair Jamie T. Richardson, Vice-Chair Curtis Arledge, Secretary/Treasurer

*Chairman Emeritus* Bob Wright 2005-2015

#### **Director Emeritus**

Mel Karmizan Board member 2005-2018

Brian Kelly Board member 2005-2015 Board chair 2015-2020

Phil Geier\* Board member 2007-2017

### Staff

Keith Wargo President and Chief Executive Officer Joe Vanyo Chief Operating Officer Bryan Klopack Chief Growth Officer Kelli Seely Chief Marketing Officer Andy Shih Chief Science Officer

### Members

Thomas Bernard Judith Benardete Scott Carpenter Jennifer Caserta Laurie Chern Barry R. Feirstein Adam Frazier Thomas Frazier II, Ph.D. William "Bill" T. Giles Darren Goode Matthew Higgins Tim Jones Aidan Kehoe Kevin J. Murray Bill O'Connor Herbert Pardes, M.D. Subriana Pierce Stuart Savitz Robert C. Schwenkel Jennifer Seidel Stephen Shore, Ed.D. Steven P. Stanbrook Cheryl Vitali

Lynn Happel SVP, Information Technology & Data Support Jennifer Podoll SVP, Constituent Engagement Stuart Spielman SVP, Advocacy Arianna Esposito VP, Services & Supports, Lifespan Programs Claudine Larocque VP, Individual and Foundation Relations

Lindsay Naeder VP, Services & Supports, Community Impact

Jaclyn Nedvin VP, People & Culture





# Designated Charity Navigator 4-Star Rating -

the highest rating a nonprofit organization can receive.



"GIVE WITH CONFIDENCE" designation



Charity .\*. Navigator

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+ FOUR-STAR +

HIGHEST level of transparency



Meets or exceeds all 20 BBB standards





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