

# The Importance of Early Diagnosis and Intervention for Kids with FASD

Families affected by Fetal Alcohol Spectrum Disorder can get access to services and support through a new program.

ased on recent epidemiological studies, it's estimated that there are over one million people with Fetal Alcohol Spectrum Disorder (FASD) in Canada, making this one of the leading causes of developmental disability in the country. FASD is a diagnostic term used to describe the range of effects on individuals impacted by prenatal alcohol exposure, which can include adverse behavioural, physical, and intellectual outcomes.

#### The power of diagnosis

Despite being one of the most common developmental disabilities in the western world, FASD is still very much a hidden disability. Diagnosis is a significant challenge because FASD can resemble other disorders, like ADHD.

"Typically, FASD diagnoses are made by a process of elimination by a multidisciplinary team that includes specially-trained physicians, developmental psychologists, and occupational therapists," explains Dr. James Reynolds, Chief Scientific Officer with the Kids Brain Health Network.

Diagnosis is critical because while there's no cure for FASD, research shows that early intervention and protective factors can improve a child's developmental outcomes.

"A nurturing and stable home environment, involvement in special education and social services, and normalizing sleep and physical exercise can all have a significant positive impact on children with FASD," says Dr. Reynolds.

#### Access to support systems

Accessing support for FASD can be challenging, and families are often unaware of existing services or face barriers to access.



Reynolds Kids Brain Health

In response to this challenge, the Fetal Alcohol Resource Program (FARP) was established in 2015 as a partnership between the Kids Brain Health Network, ABLE2 (previously Citizen Advocacy Ottawa), CHEO, a pediatric health-

care and research centre in Ottawa, and the Children's Aid Society of Ottawa to connect individuals and families living with FASD in the Ottawa region to support services in their community. Now embedded as a permanent service at ABLE2, the FARP provides direct services to families by offering individualized clinical family support, hosts support groups for children, youth, and adults with FASD and caregivers, and helps with service navigation and advocacy in the community. The FARP also provides capacity-building through high-level training in multiple sectors such as mental health, housing, justice, and education. Since its inception, the FARP has provided customized FASD training workshops to more than 5,000 health practitioners, professionals, and frontline service workers. Last year alone, the FARP provided direct clinical support to over 80 individuals with FASD and their families and responded to over 100 requests for professional consultation.

"This program is bringing together key stakeholders to take collective ownership of the challenges faced by individuals and families impacted by FASD and coming up with coordinated responses on how to support children and families with this disorder," says Dr. Reynolds.

# A Robust Support System for Families Affected by FASD

Fetal Alcohol Spectrum Disorder (FASD) is a condition that lasts a lifetime. It occurs when a developing baby is exposed to alcohol during pregnancy. Children with FASD can have behavioural, intellectual, and neurological problems.

onia was diagnosed with FASD when she was eight years old. Her parents, France and Joe, share her

It took more than five years for France and Joe to get their daughter Sonia accurately diagnosed. They recognized red flags at a young age with Sonia's attention and memory. At three years old, Sonia was diagnosed with severe ADHD, but France and Joe knew that Sonia's condition was different. They suspected it was FASD.

"The typical interventions, tips, and tricks for ADHD didn't help Sonia because what she had was a brain injury," explains France.

Sonia also struggled academically. She had trouble staying on task, was easily frustrated, and had outbursts in

After years of trial and error, Sonia's parents were able to get a psychiatrist report that ruled out other disorders like autism or opposition defiance disorder and recommended an assessment for FASD. With that referral, they were able to get Sonia to a specialized FASD assessment clinic.

#### The benefits of a diagnosis

According to Sonia's mother, "getting the diagnosis helped understand where Sonia was coming from." France says that it helped them reframe the challenges they faced, especially in school. "It wasn't that Sonia had behavioural issues, it's that she had a brain injury, to her needs," she says.

and the environment wasn't tailored Her parents say the diagnosis also helped Sonia understand why her brain

works the way it does.

"She knows she's different, but at least now she knows why," says France. "It helped her understand that she's not a bad kid."

#### Finding a support system

Because Sonia's parents suspected that she had FASD before the official diagnosis, they were already in touch with the Fetal Alcohol Resource Program (FARP). The most significant support they received from the FARP was with Sonia's education. The family was assigned an FASD worker who acted as a liaison with Sonia's school. The FASD worker educated Sonia's teachers and faculty about FASD and helped develop a curriculum that focused on Sonia's strengths. Sonia's parents say that the school has been incredibly supportive, receptive, and willing to learn.

"Her teacher recently told us that Sonia completely opened his eyes and changed how he teaches kids with spe-

Sonia and her family also take advantage of the support groups organized by the FARP.

cial needs in general," says France.

"It's extremely important for our

daughter to spend time with kids like her, so she feels less alone," says France. "The support groups have been helpful for us too, knowing there are families going through similar issues."

that the FARP plays in raising awareness for FASD. "They're helping educate the com-

France and Joe appreciate the role

for kids like Sonia," says Joe. 🤜

munity and develop a support system

The Kids Brain Health Network (KBHN) is supported by the federal Networks of Centres of Excellence program and hosted at Simon Fraser University. The KBHNs vision is to fund innovative research to find solutio to help children with neurodevelopmental disabilities and their families.

To learn more about the Fetal Alcohol Resource Program, visit able2.org/programs/fetalalcohol-resource-program. To learn more about the Kids Brain Health Network, visit kidsbrainhealth.ca.

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INSIGHT

# Unlocking the Mysteries of the Brain Is More Critical Now Than Ever Before

Brain Canada brings together brilliant scientists to drive innovative research.

Michele Sponagle



**Dr. Viviane Poupon** President & CEO, Brain Canada

espite the crucial role it plays in our ability to exist and function, the brain isn't fully understood and continues to hold many mysteries.

Dr. Viviane Poupon, a highly-accomplished neuroscientist, was appointed Brain Canada's President and CEO in September 2020. She leads the national organization's efforts to fund innovative brain research across Canada. "We need to understand the brain better because it's the body's most complex organ," says Dr. Poupon. "If we don't understand the healthy brain, there's no way we can successfully treat the brain in illness. It's very important to find solutions for when the brain stops functioning optimally."

#### Finding answers to critical questions

Since its founding more than 20 years ago, Brain Canada has worked to enable and support brain research, using an interdisciplinary approach, convening and connecting researchers, partners, and donors. "We really want to foster collaboration and bring together people and organizations that haven't been working together historically," says Dr. Poupon. "That's where the breakthroughs can happen."

By sharing knowledge and scientific data freely among stakeholders, dramatic results can be achieved, as the world saw in the unprecedented rapid development of COVID-19 vaccines. Brain Canada hopes that by fostering collaboration and removing information silos, all parties can advance and accelerate the understanding of the brain. Its multi-faceted approach is currently supporting more than 300 grants, involving over 1,000 scientists and 115 institutions.

#### Key partnerships for advancing research

The Canada Brain Research Fund, established in 2011, is a partnership between Brain Canada and Health Canada designed to encourage Canadians to increase their support of brain research and to maximize the impact and efficiency of those investments. This visionary commitment by the federal government will ensure that Canada continues to be among the leaders in the global challenge to understand brain function and brain diseases. More than simply contributing public money to this vital cause, the matching nature of the fund is stimulating and rallying private donations and other non-governmental funders to  $support\,transformative\,brain\,research.$ 

"The Government of Canada recognized neuroscience as one area that might have been under-funded in the past," explains Dr. Poupon. "At the same time, we had outstanding assets in the research community, and it was clear that the impact on the health of

Canadians, if we could work together, would be significant."

Due to the pandemic, certain subject areas have increased urgency, like neuro degeneration — the brain health of seniors. "We've seen that people in long-term care facilities are very susceptible," notes Dr. Poupon. "We need a sustainable health care system and access to better care for seniors so that they can stay at home as long as possible."

#### Focused on the future

COVID-19 has also emphasized the urgent need to address the gaps in mental health care. "The pandemic has made it even more obvious that the time to act is now, and that we must invest in neuroscience to understand the brain's role and to develop optimal treatment options," says Dr. Poupon, underlining Brain Canada's new mental health initiative, the \$4M Bell Let's Talk — Brain Canada Mental Health Research Program, which aims to advance the science around mental health by awarding grants to innovators in the field.

Brain Canada also strives to support the next generation of researchers through its Future Leaders in Canadian Brain Research program, which provides funding to young researchers just beginning their careers. "It's our way of supporting really innovative ideas," says Dr. Poupon. "We bet on the scientists we think are going to be the future stars in neuroscience."

With so much yet to achieve, this is an ideal time to help advance brain research in Canada. Learn more about how you can help fund brilliant brain research today at

This article was sponsored by Brain Canada.

braincanada.ca.





# Living Life After a Stroke

It's important for people who have recently experienced a stroke to get access to the right support.

challenges, rebuilding a fulfilling life

after stroke is possible with the right

period after returning home from the

hospital can be the most challenging

ment process people go through as they

leave the hospital and return home.

They're coping with significant change

across every part of their lives, from their

mobility, to their relationships to their

emotions and self-confidence," says Dr.

Michelle Nelson, Chief Knowledge and

Innovation Officer for March of Dimes

accessing community supports isn't

always easy. But according to Dr.

Nelson, there's mounting evidence that

community organizations like March of

Dimes Canada have a vital role to play

in helping stroke survivors navigate

uniquely positioned to bring care

"Community organizations are

During this time, finding and

Canada's After Stroke program.

For many stroke survivors, the

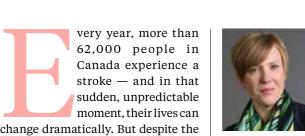
"After a stroke, there's a huge adjust-

Janice Tober

supports.

part of the journey.





Dr. Michelle **Health Services** Researcher & Chief Knowledge & Innovation Officer. March of Dimes

and to tailor it to the unique needs of each person, recognizing all the things that can contribute to someone's wellness," says Dr. Nelson. March of Dimes

closer to home.

Canada's After Stroke program works one-on-one with stroke survivors to explore their

needs, establish goals, build plans to achieve them, and assemble a helpful network of local programs, services, and supports. The program is also available to family members and caregivers who need support adjusting to their new roles.

"Life after a stroke may require some adjustment, but with the right support, it can be rich, meaningful, and full of all the things you enjoy," says Dr. Nelson. 🤏

If you or someone you know has had a stroke, call 1-888-540-6666 or visit afterstroke.marchofdimes.ca

This article was sponsored by





The Azrieli Foundation supports scientists and patients navigating the brain health journey.

Anne Papmehl

he Azrieli Foundation is leading the way in philanthropy through innovative programs, grants, and initiatives that catalyze change. The foundation was established in 1989 by David J. Azrieli, a Holocaust survivor.

The foundation supports brain health research and patient care, with a strong focus on neurodiverse conditions such as autism and Fragile X syndrome.

#### From bench to bedside: a virtuous cycle of brain research and patient care

The foundation's holistic approach reflects its philosophy that scientific research and patient care are linked. "We believe that this integrated approach will lead to a virtuous cycle where breakthroughs in labs will help people and observations in the clinic will drive breakthroughs in the labs," says Dr. Naomi Azrieli, CEO and Chair of the Azrieli Foundation.

This approach also offers the potential of a scientific discovery benefitting other areas. "Neurodevelopmental research has a huge ripple effect," says Dr. Azrieli. "An insight from research in one area like autism can open new pathways for treatments for other disorders."

#### Brain health research: the last frontier of science

Brain research is often referred to as the last frontier of science and researchers are its pioneers. But scientists aren't the only pioneers in this journey. "Any family that has had to live with a brain disorder knows what it's like to live like a pioneer, stepping into uncharted territory without the aid of any scientific map or treatment options," says Dr. Azrieli.

As brain research enters a new era, Dr. Azrieli believes that more human capital in mental health research, treatment, and services will give patients and families more tools to live independent, meaningful, and productive lives. "Scientists and clinicians are on the verge of major advances in understanding and care," she says. "There's never been a better time to do brain and mental health research."

To learn more, visit azrielifoundation.org.

This article was sponsored by the Azrieli Foundation





the transition.

# **Reducing Inequity** in Dementia Research with the Alzheimer Society of Canada

Dementia affects hundreds of thousands of Canadians, but it's still a stigmatized and underfunded condition, especially for Black, Indigenous, and people of colour (BIPOC) communities. A new initiative from the Alzheimer Society of Canada will help fill important gaps in research.

ontrary to popular

Liza Agrba

belief, dementia isn't a normal part of aging - though we still don't know exactly what causes it. Research is actively underway across Canada to find better treatments, improve quality of life for people living with dementia and their caregivers, and pave the road towards a cure. However, not all people with dementia are well-represented in research studies. Funding and facilitating effective, equitable research that encompasses the diversity of lived experiences across Canada is crucial to improve quality of life for affected Canadians. More than 500,000 Canadians live with dementia — a number projected to double in less than 10 years.

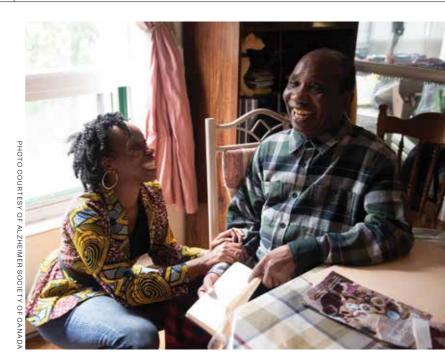
The Alzheimer Society of Canada is a nationwide charity that provides support services to people with dementia and their caregivers, funds and facilitates research, and works to enhance public knowledge about Alzheimer's disease and other dementias.

It's latest effort — the Dementia Journey Survey — aims to gather information and understanding about the experiences of BIPOC community members living with dementia. "BIPOC people aren't well-represented in dementia research," says Ngozi Iroanyah, Coordinator of Research at the Alzheimer Society of Canada. "There's a serious gap of information around these populations, and that means that policies, programs, and strategies don't speak to their needs and experiences. Because of that, people may feel even more left out and excluded, and not seek out treatment in time. People in these communities fall through the cracks — or rather, gaping holes — in the research."

#### Stigma can prevent access to appropriate treatment and support

While there have been significant strides in its diagnosis and treatment, dementia is still a highly-stigmatized and often misunderstood disease. About 60 percent of Canadian family physicians say that they feel illequipped to help their patients navigate dementia, and there's currently no standardized treatment protocol once a diagnosis is made. Compounding the problem is the inequitable distribution of research across different ethnic groups, which serves to further marginalize individuals living with dementia and their caregivers, through a lack of

culturally-specific dementia tools.





The Alzheimer Society of Canada's latest effort — the Dementia Journey Survey — aims to gather information and understanding about the experiences of BIPOC community members living with dementia.

#### The Dementia Journey Survey focuses on the experiences of dementia within BIPOC communities

Stigma and embarrassment can also prevent those living with dementia, especially BIPOC individuals, from sharing their experiences with researchers. As a result, those researchers, as well as physicians and policy writers, are ill-equipped to support those living with dementia in an equitable way. From underpinning research about causes and treatments to design-

To close the equity gap in dementia

ing effective treatment protocols, more data is needed.

treatment and support, the Alzheimer Society, in collaboration with the College of Family Physicians of Canada, has launched the Dementia Journey Survey. The 10-minute survey is open to all people living with dementia and their caregivers but is especially aimed at BIPOC communities. "We're trying to move toward deeper community engagement whereby we have the experiences, voices, and perspectives of underrepresented communities informing the things we do," says Iroanyah. The survey is accessible online through the Alzheimer Society website,

alzheimer.ca/survey. Hundreds of unique programs are available across the country through the Alzheimer Society. From referral services and caregiver support to brain health programs and COVID-19 resources, there's a good chance a program near you can help. 🤜

If you live with dementia or care for someone who does find your local Alzheimer Society today by visiting alzheimer.ca.



Alzheimer This article was **sponsored by** Alzheimer Society of Canada.





INSIGHT

# Removing the Stigma Around Addiction and Mental Health Issues Opens the Door for Getting Help

The Canadian Centre for Addictions provides coping strategies to those with addictions, leading to success.

Michele Sponagle



Certified Addiction Counsellor, Canadian Centre for Addictions

anadians with mental health issues are two times more likely to also experience substance abuse. This stat from the Mental Health Commission of Canada has come into sharp and increased focus due to COVID-19, as both mental health issues and substance abuse continue to grow. In fact, a recent poll from NANOS Research showed that substance abuse is on the rise nationally, with nearly a quarter of adults reporting increased alcohol consumption. This data underscores the urgency of addressing addiction issues.

#### Treating the core issue

Fortunately, there are effective treatments available. "Addiction is always the symptom of something else," says Seth Fletcher, Director of Addiction Services at the Canadian Centre for Addictions, a private treatment facility in Port Hope, ON. "It tends to be a person's best solution to an alreadyexisting problem. It's just a temporary escape. It numbs emotions and feelings, but it doesn't address the core issue. There's a very high prevalence of mental health issues when it comes to addiction."

One of the first steps is to identify the underlying issue, whether it's anxiety, depression, physical pain, or past trauma. Regardless of the cause, addiction is an attempt to self-medicate. That's why just treating the symptom is ineffective. "A person can go to detox, for example, and they can stay there for three or four weeks," explains Fletcher. "But if they come out and don't have any new coping mechanisms or healthier strategies to manage, whatever the reason was that they were using drugs in the first place, they're likely to go back to what they've always known. They haven't learned enough about the why."

#### Taking the first step

The optimal treatment plan drills down to this "why" and provides tools to set up an addicted person in recovery for su cess. "If we can promote those resiliency skills and address the underlying issues, all of the sudden they're not looking for that escape," says Fletcher. "They're not looking to numb those emotions and feelings because they're already being addressed with help from certified addiction counsellors."

For many people with addictions, the first step to making positive change and leaving addictions behind is the most difficult. Families and loved ones can also seek professional help for an  $intervention\,that\,allows\,them\,to\,outline$ their boundaries and the consequences for the addicted person if they continue their behaviour. This can be a motivating factor for getting treatment, along with a realization that the substance abuse isn't worth what it's costing the addict, whether it's their marriage, job, or children. Ideally, he or she seeks help before hitting rock bottom.

#### Overcoming the stigma

Addicts may also be hesitant to get treatment because of the stigma. The fear is that other people may see them as weak. "It's okay to ask for help," Fletcher says. "That's actually the best thing you can do for yourself. If your car weren't operating properly, you wouldn't hesitate to take it to a mechanic. If we treat ourselves the way we do other things in our lives, we'd be much better off. There should be no stigma and no shame in seeking help."

## Sometimes We Don't See That We Need Help

A mix of mental illness and addiction can cloud our reasoning and self-awareness

Sometimes. we don't think it's as bad as it really is

Sometimes. we need someone to see it for us

**Interventions** can help



#### **Identify**

#### Contact an accredited specialist

A trained specialist has the resources and experience to help break through to an addicted person.



#### **Build a Plan**

#### **Gather information**

The interventionist will prepare you on how the actual intervention will proceed, including how to deal with a refusal to get immediate treatment.



#### Plan ahead

Decide on your boundaries. Be prepared to defend them. Rehearse the plan to reduce emotional stress on the day of the intervention.



#### **Engage**

#### Trust vour

commitment Remember, there are only two important reasons for having an intervention: 1. Protect yourself, and 2. Get the sufferer help.

Want to know more about how to get help dealing with addiction for yourself or a loved one? Call 1-855-971-0715 or visit

canadiancentre-

foraddictions.org.

This article was sponsored by the Canadian Centre for Addictions.





## Michael Landsberg Goes on the Record About Mental Health

Michael Landsberg, TSN legend and founder of the #SickNotWeak Foundation, opens up about his experience with depression and offers his advice for those living with mental illness, urging everyone to ask themselves, "Do I experience joy?"

#### What can Canadians do to reduce the stigma associated with mental illness?

**Michael Landsberg:** If we could embrace the concept that mental illness is a sickness instead of a weakness, we could overcome the stigma. Today, people see depression as being self-inflicted, and believe that those suffering from it weren't strong enough to overcome it — that's incredibly damaging, especially to the person suffering from mental illness.

#### What advice do you have for readers to improve their mental health?

ML: There are a lot of Canadians who have no idea that they're sick. Take inventory of yourself, especially throughout the pandemic. Ask yourself, "One year ago when things were normal, how did I experience life? What was my ability to experience joy like?" I call this the basic joy test — what's one thing in your life that brings you simple joy? For me, it's my first sip of coffee in the morning. I ask myself, "I enjoyed this a year ago, but do I still enjoy it?" And if I don't, it's a sign that I need to address what's going on, because the loss of that ability to experience joy is universal.

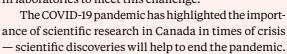
Read the full interview at healthinsight.ca.

# Investing in Research Is Key to Maintaining Brain Health in Canada

Now is the time to increase investment in health research that will promote brain health in Canada.

Charles Bourke

eurological conditions — disorders that affect the brain and nerves — are the leading cause of disability and second cause of death worldwide.¹ There's an urgent need to develop innovative treatments and cures for hundreds of diseases and injuries that affect millions of Canadians. Understanding how the brain works is key to addressing this complex challenge, and Canadian researchers from coast to coast are working diligently in laboratories to meet this challenge.



We now need to ensure that the Canadian scientific research ecosystem is prepared and ready to meet Canada's next health challenges, many related to brain health. However, fundamental research remains chronically underfunded by the federal government. For several years now, the Canadian Institutes of Health Research has been forced to reject more than 82 percent of project proposals because of underfunding. This means that many research studies that could lead to the next blockbuster drug for brain diseases or brain cancer aren't being funded. According to the latest data from the Organisation for Economic Co-operation and Development Canada is the only country in the G7 whose investments in research and development have steadily declined in the last 15 years.

Now is the time to increase investment in health research to support the laboratories and highly-qualified personnel who will make life-changing discoveries that will promote brain health in Canada

Discoveries that lead to therapies and new breakthroughs stem from years of research to understand the basic science of how the brain works. To meet the growing challenge posed by neurological conditions, the Canadian government needs to significantly increase its funding for health research. It's an investment in Canada's health and prosperity now, and for the future.

Feigin et al 2019 Lancet 18, 459-480 doi.org/10.1016/S1474-4422(18)30499-X



Dr. Charles
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President,
Canadian
Association for
Neuroscience

To learn more, visit

can-acn.org

This article was sponsored by the Canadian Association for Neuroscience.





# Important Research Is Saving the Lives of People Living with Epilepsy

Sudden unexpected death in epilepsy (SUDEP) is a rare but tragic occurrence. Epilepsy Canada is supporting critical research to reduce risk.

Anne Papmehl

pilepsy is a condition of abnormal electrical activity in the brain characterized by recurrent seizures. Approximately 360,000 Canadians live with epilepsy and it affects one in 100 people worldwide. Epilepsy can start at any time in life, affecting all facets of an individual's physical, mental, and emotional well-being. In rare cases, it can be fatal.

Sudden unexpected death in epilepsy (SUDEP) refers to the sudden death of a person with epilepsy where no other cause of death can be determined. "The most common scenario is a person living with epilepsy who is most often found to have died overnight," says Dr. Elizabeth Donner, Director of the Comprehensive Epilepsy Program at the Hospital for Sick Children and Board Member and Chair of Epilepsy Canada's Scientific Review Committee.

The risk for SUDEP is highest in people



Dr. Elizabeth
Donner
Comprehensive
Epilepsy Program
Director,
The Hospital for
Sick Children
Board Member,
Epilepsy Canada

with uncontrolled and recurring full-body convulsions, particularly at night or during sleep. "The tired, drowsy, or sleeping brain is more prone to produce a seizure and for reasons that scientists are working to understand, some seizures may affect the areas of the brain that control breathing and heart rate," says Dr. Donner.

#### Knowing who's at risk can help save lives

Originally thought to be less prevalent in children than in adults, Dr. Donner has discovered that SUDEP is equally as common in children. The good news is that there may be a way to help identify children at higher risk.



Gary Collins President, Epilepsy Canada

In a 2017 paper published in The Journal of Pediatric Neurology, Dr. Donner and her colleagues studied 77 generalized convulsive seizures in 40 children between the ages of one and 17. They found that children who showed brain suppression tendency during their

seizure also showed a unique posture during their seizure. By identifying children at highest risk, Dr. Donner hopes that we can develop strategies to reduce risk.

Research like this is funded by Epilepsy Canada. "Research takes time, and it's incredibly expensive," says Gary Collins, President of Epilepsy Canada. "So in order to improve the lives of people living with epilepsy, we need time and money."

Help fight epilepsy by donating or volunteering for the life-changing research that's being funded by Epilepsy Canada by visiting epilepsy.ca.

This article was sponsored by Epilepsy Canada.

Epilepsy Canada Canada





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at autismspeaks.ca/walk2021