

The Campaign for the Pacific Autism Family Centre

Building Potential for a Brighter Future



Key Messages

1. Autism Spectrum Disorder is a growing condition that is impacting our society in profound ways

- ✓ 1 in 88 children affected, with symptoms typically appearing in the first 3 years of life
- ✓ Boys affected 5 times more than girls; 1 in 54 boys has an ASD
- ✓ Affects a person's social relationships, communication, interests, and behaviour which significantly impedes their ability to learn, work and lead a fulfilling life
- ✓ Presents in a wide range of severities making it harder to diagnose and treat – some may attain PhDs while others may need 24 hour care
- ✓ A complex condition spanning medicine, education, social justice, homelessness, corrections, community
- ✓ A ticking time bomb: numbers expected to rise steadily
- ✓ Devastating to families both financially and in human terms: Early intervention costs up to \$60,000 a year per family, with only a small portion covered by the province; can cost \$3 million over a lifetime per person
- ✓ No fulsome approach to the dissemination of knowledge and resources to families about best practises, new research, treatments and support; families essentially left to their own devices
- ✓ A tragedy because today there are effective treatments available

2. An issue whose time has come

- ✓ Great strides have been made in many aspects of this complex condition
- ✓ Many pieces of the puzzle are in place; now we have to put them together
- ✓ It takes a village – we have to help families, but we have to educate whole communities

- ✓ A special kind of interdisciplinary organization is needed to leverage this knowledge and develop the new applied tools and solutions
- ✓ Leverage is needed to bring new innovations into the actual lives of individuals and their families
- ✓ Knowledge translation and dissemination – get the information to communities in a timely and accessible fashion; develop a holistic set of approaches that are evidence based and proven effective
- ✓ Protect desperate families from misinformation
- ✓ No one group can do this alone – communities, schools, healthcare systems, and governments must work together

3. British Columbia is poised for leadership

- ✓ BC is emerging as a global hub, attracting some of the top researchers and practitioners in the field
- ✓ Unique ‘convener’ environment means BC has already built a strong community network; poised for action
- ✓ Visionary founders have brought the community together to tackle this problem
- ✓ We can build human potential and safeguard our future competitiveness and prosperity
- ✓ Autism is emerging as one of the most pressing issues of our times
- ✓ Once-in-history chance for British Columbia to be first and best and position itself as a global leader
- ✓ Government has made a visionary \$20 million contribution;
- ✓ Opportunities to think differently about treatment, education, prevention, health, wellness, person- and family-centered care
- ✓ Enormous potential to impact many parts of modern life

4. A Vision for a Centre unlike any other in Canada, if not the world

- ✓ The next set of solutions will be at the convergence of a wide variety of disciplines and include families, communities and a wide range of thinkers
- ✓ A physical structure in partnership with government, healthcare, education, and the community
- ✓ The whole will be greater than the sum of the parts – capitalizing on the experience of families and positioned to link research, teaching, direct care
- ✓ A hub of innovation. At last, a place to go for families seeking reliable, unbiased information and help, no matter where they live in BC
- ✓ Truly interdisciplinary – strong technology platforms, information-sharing, outreach, research: a locus of unprecedented collaboration
- ✓ Providing the platform for creating actual models and clinical approaches and continuously evolving/improving them in real time

5. Leveraging what we already know; maximizing the potential of many efforts

- ✓ Building on the outstanding work of many other centers and universities
- ✓ Knowledge translation – creating applied models from the fruits of basic and clinical research
- ✓ Creating an environment in BC of unprecedented collaboration and collegiality
- ✓ The networks, the brain power, the experience, and the critical mass to tackle important parts of this puzzle in a way nobody else can
- ✓ Build a new generation of researchers, specialists, attract the best and brightest here
- ✓ If not now, when? If not us, who?

6. Investor impact: Shifting the paradigm and building a new future

- ✓ Today's PAFC donor will be at the frontier of 21st century healthcare, education, social justice, and social innovation
- ✓ Canadian and global impact
- ✓ A lifeline impacting every aspect of society and community
- ✓ Advances in genetics, neuroscience, earlier diagnosis, brain plasticity, intervention – all the puzzle pieces are there; we just have to put them together
- ✓ Opportunity to have an immediate impact today and for generations
- ✓ The world will be different because of what you do

Building Potential for a Brighter Future

What if I told you that a curious, but fast-growing neurobiological disorder is suddenly affecting our children at rates so high it exceeds juvenile diabetes, pediatric AIDS, schizophrenia, cancer, and cystic fibrosis combined?

What if I told you that this condition afflicted people across their lifespan, from childhood to adulthood, dramatically affecting their capacity to learn, communicate, work, contribute, and lead productive lives?

What if you heard that the numbers are increasing at an alarming rate, with 1 in 88 children affected now, and as many as 1 in 54 boys predicted to be born with it in the next five years?

Would you be surprised to discover that there is no clear plan to help support these people and their families when they receive this frightening diagnosis and no centre to help them navigate through the daily challenges it brings?

What if you knew that this condition costs as much as \$3 million per person in a lifetime?

What if I told you that vital keys to understanding it had already been found, but that families are suffering unnecessarily because there is often no way to get reliable information and support to communities in a timely fashion?

What if I told you that this condition is Autism Spectrum Disorder and that it is among the most complex and fastest-growing medical diagnoses affecting young people today, with the ability to wreak havoc with their future potential, quality of life, and the competitiveness and prosperity of our communities?

Would you be surprised to find out that, given the complexity of the diagnosis, families are often left to piece together their own treatment plans integrating medicine, schooling, private therapies, and community supports?

Would you think this is something we as a province and a nation should address right away?

Imagine if we could better integrate and harness all the resources we have available and help BC families put them together in the best and most cost-effective way possible to meet their child's specific needs? Would you be excited to see our community stepping up for our kids and families and, in the process, propelling BC to the forefront of addressing one of the most complex medical challenges of our time?

Right here, right now, we have that opportunity.

Forward-thinking BC families, caregivers and researchers have an exciting, entrepreneurial and visionary plan to tackle this problem head on and, in the process, to position BC as a proud global leader. You can be a part of this team.

An Issue Whose Time Has Come

While we seldom hear about it in the media, communities today are facing an unacknowledged epidemic that is beginning to impact our future in profound ways. Just a decade ago, a marked spike in the diagnosis of Autism Spectrum Disorder began to register among researchers, caregivers, schools, and families. This little-understood condition, characterized by a wide range of developmental disabilities, began to be diagnosed in more than 1 in 150 children worldwide.

“What this diagnosis does to families can’t be underestimated. But its effects are being felt by all of us, in every aspect of our communities. More and more, we will begin to recognize that this is something that affects us all.

The Futures Campaign is about a whole province coming together to leverage the resources of individuals, governments, families, and communities. It’s about putting BC out front in tackling an issue critical to the quality of life and essential to building our province’s future competitiveness and prosperity.

By investing wisely and strategically, we can build an environment of unprecedented collaboration and creativity. We can make BC a world leader, able to design effective and cost-effective ways to help ensure this growing population reaches its full potential.”

**Sergio Cocchia
PAFC Founder**

Since dramatic increases began to be noticed a decade ago, the disorder has continued to accelerate at a striking pace. From 1 in 150 children then, ASD now affects 1 in 88 children worldwide. It affects boys more than 5 times as often as girls, with 1 in 54 boys having an ASD.

Without immediate attention, this disorder will have a dramatic effect on the quality of life for families, in realizing the potential of our future citizenry and workforce, and in the successful future functioning of our communities. This “ticking time bomb” phenomenon is not unique to BC, Canada or North America, but is being seen all around the world, in all races, all nations and all socioeconomic groups.

While children are now diagnosed faster than ever before – usually between the ages of 3 and 5 – the effects of Autism Spectrum Disorder are felt throughout the lifespan, often with devastating results.

A Modern Enigma

How to effectively treat and manage Autism Spectrum Disorders is something communities everywhere are struggling to understand. Because each person is affected differently, each treatment plan must be unique and encompass a wide range of medical and social supports, including home therapy, schooling, psychological counselling, emotional support, diet and nutrition, to name a few. Finding proven and cost-effective answers will represent one of the most important medical, research and social frontiers facing humanity in our times.

“Even the most affluent, knowledgeable and savvy parents can end up insular, exhausted, desperate, and isolated from the world. But for families without resources, for those who don’t speak English, or for those who can’t afford a caregiver, the situation can be even more challenging.

The Futures Campaign is about meeting these families half way – providing a place for them to go to get information, to find a support system and to become co-researchers and co-creators.

We have the pieces of the puzzle in BC. Families are a wealth of knowledge and experience. BC researchers are out front in the world. With the Pacific Autism Family Centre, we now have a way to put the puzzle together.”

**Sharon Baxter
Applied Behavioural Analysis Specialist**

BC has begun to emerge as a global hub of research and innovation in the autism field. Partly due to our culture, partly due to our existing network of innovative educational and medical programs for special needs children, partly due to the excellence of forward-thinking researchers and practitioners drawn to our innovative universities and community colleges, and partly due to the dynamic community of visionary parents and families that is emerging here, BC has all of the elements in place necessary to be a world leader.

In recent years, Sergio and Wendy Cocchia, parents of a child on the spectrum and recognized community leaders and philanthropists in the province, have embarked on a journey to capitalize on BC’s strengths as a constituency poised for leadership in tackling the autism enigma. The Pacific Autism Family Centre Foundation, the fundraising entity they established, is launching a campaign to raise \$13 million toward the creation of a new \$28-million Autism Centre so comprehensive and so forward-thinking, it will not only be the first of its kind in Canada, but stands to become a global model for how communities can best address this complex and often misunderstood condition.

\$20 Million has been secured from the Government of British Columbia toward capital costs. Of the \$13 million to be raised from private sources, \$8 million will cover the remaining building costs, and a further \$5 million will seed the Centre's operating endowment.

Today's investment of \$13 million will not only help us reach out to desperate, needy and deserving families today, but the effects of the establishment of this Centre will ripple out and impact every aspect of modern culture and society, from education, medicine and social justice to corrections, homelessness and our understanding of modern genetics, brain science and the science of learning.

What is Autism?

No one knows what causes ASD or why its prevalence is rising so quickly, but at present it is believed to be the result of a complex array of genetic and environmental factors. While many suspect that autism results from an interplay of environmental and genetic causes, no definitive scientific proof for specific environmental causes has yet been found.

"Autism is a condition that affects whole communities. As such, we need an integrated solution that includes community education, teacher learning, the training of specialists, more awareness for medical practitioners, and support for siblings, parents and extended families.

Governments can't do it alone. The Pacific Autism Family Centre is about coming at this together. It's about saying – let's pool our resources and work with governments to get out front of this issue. Let's be the leader and show the world how this could be done."

**Wendy Cocchia
PAFC Co-Founder**

Every child is Different

What makes ASD so difficult to detect and treat is that it affects each person very differently. Some are socially awkward, but gifted in a few narrow domains. Others are significantly impeded in their ability to learn, work and lead a fulfilling life. In more extreme cases, some may need to spend their lives under constant supervision or even in 24-hour one on one care.

Because of the vast range in severity across the domain, people with autism are often described as "on the spectrum". Some with milder forms of Asperger's could get a PhD, but may have clumsy motor skills, difficulty understanding other people's facial expressions and emotions and would have great difficulty functioning in a complex organization. On the other hand, they may be extremely gifted with computers or excellent at drawing, 'savant' within one or two narrow, but high-potential domains.

Autism has been around long before it was named and, in previous generations it was likely often misdiagnosed. In 1801 a young physician in France, Jean Marc Itard, described a young boy Victor who was known as "the wild boy of Aveyron". In 1919 a Swiss psychiatrist, Eugen Bleuler, was the first to coin the term "autism" to describe the idiosyncratic, self-centred thinking and related withdrawal of people with schizophrenia. But the most significant breakthroughs in understanding began in 1943, when Dr. Leo Kanner, a Jewish American

psychiatrist, described 11 children who had "autistic disturbances of affective contact". In his seminal paper published in the journal "The Nervous Child", he wrote: "These children have come into the world with an innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical and intellectual handicaps." Around the same time, in 1944

and on the other side of the world, Austrian psychiatrist Hans Asperger independently described four children with "autistic psychopathy in childhood". Asperger called these four children "little professors" because of their ability to talk about their favorite subject in great detail.

Over time, he noticed that many of the children he identified used their special talents in adulthood and had an excellent career. One of them became a professor of astronomy and solved an error in Newton's work. Another went on to win a Nobel Prize in literature.

Did You Know?

- **Today, autism affects 1 in 88 children**
- **It is increasing in prevalence, with experts predicting 1 in 54 boys will be affected within 5 years**
- **90 percent of all children with disabilities in crisis and at risk of out-of-home placement have autism**
- **Autism treatment costs can be as much as \$60,000 per year for children up to age 21, a number expected to double in the next decade**
- **A Harvard study estimates that the cost of 1 person with autism who goes untreated will be \$3.2 million over their lifetime**
- **ASDs occur in all racial, ethnic and socioeconomic groups**
- **ASDs are 5 times more common among boys (1 in 54) than girls (1 in 252)**
- **People with autism often demonstrate obsession with a narrow range of subjects, difficulty managing conversations or feeling empathy, and some enact repetitive movements such as walking on tiptoes, flapping and hand-wringing. These movements are called "stimming", and it's one of the strategies people with autism use to manage what many describe as a "scrambling" of thoughts in their brains.**

Asperger's descriptions formed the basis of what is known as Asperger's syndrome or "high functioning autism" today.

Autism is a frightening diagnosis for families, both financially and in human terms. Often, the journey begins when an infant fails to respond to social cues or a child who otherwise looks and acts "normal" fails to begin speaking by the age of 2 or 3.

Sometimes, a toddler may begin to have seemingly irrational outbursts of prolonged rage, violence and tantrums that are excessive in severity

and duration. Every parent dreams of seeing their child reach their full potential in life. They observe their child carefully, worrying about their health and about how they are developing. When parents begin to notice these warning signs, panic begins to set in.

Their family doctor may suggest looking into the possibility of Autism Spectrum Disorder. At that point, parents tumble headfirst into a system plagued with obstacles and delays. In most areas of the province, obtaining an autism diagnosis in your home community is not possible so families must travel at their own cost. Wait times to obtain an assessment appointment are lengthy – sometimes even years. For many parents, by the time they are able to obtain an autism diagnosis they have already been through a stressful, expensive and frustrating endeavour.

After a diagnosis is made, families are launched into a complex world of specialists, therapies and government funding without a central person or place to turn to for help to navigate the system. Underlying families' efforts is the knowledge and sense of urgency that each delay costs their child treatment opportunities and potential positive outcomes that could be gained by early intervention.

"You feel so helpless watching your child go through this. It's really, really lonely.

Our son was very anxious, couldn't control himself in public, just inconsolably melted down all the time. You'd be in the grocery store, and because he looks normal, people would yell at my wife and me and tell us what a brat we were raising. But with kids like this, strictness, authority and traditional discipline don't work. It's not about being spoiled; it's about how the child's brain is wired. They just can't function and reason the way other kids do. A lot of these kids never have a real friend, are the butt of judgement and jokes all their lives. And what happens when they're out there in the world as adults and no one is there to protect them?"

**William
Parent**

A Major Challenge for the 21st Century

Not only does autism stand to seriously inhibit the potential development and productivity of our future citizenry and workforce, it has enormous financial implications as well. Estimates are that treatment costs up to \$60,000 per year to care for a child who is severely affected by autism, and a recent Harvard University study calculated the lifetime costs for care and lost productivity to exceed \$3.2 million.

Already, some are estimating that a significant proportion of homeless people and those in the prison population are in fact untreated or undiagnosed adults with autism who have trouble coping alone and whose propensity to become victims of physical and sexual abuse is very high. Because of their socially naive tendencies, people with the disorder make easy marks for unscrupulous people. In the US, studies estimate that 15 to 20 per cent of homeless people have autism spectrum disorders.

Did You Know?

- **In BC, there are currently an estimated 506,000 people with autism**
- **There are 8,500 children and youth in the province diagnosed with an autism spectrum disorder; over 1,000 children 0-6 and over 7,500 children aged 6 through 18**
- **Provincial Wait Lists for diagnosis can run 9 to 12 months**
- **Estimates state that as much as 65 percent of the lifetime \$3.2 million costs (\$2 million per child) could be saved with early intensive therapy. Potential savings (900 x \$2 million) = \$1.8 billion**
- **Early intervention therapy needs to be intensive (1 to 1 active engagement for a minimum of 25 hours per week) to be effective**
- **Right now, the burden is on families, schools and the province for a condition that deserves treatment**

Families Need a Family

Canadians value their universally-accessible healthcare system, and most British Columbians assume that such a diagnosis would automatically trigger a reliable, integrated and comprehensive system of supports. But this is not the case.

The BC government offers all children with special needs, including those with autism, foundational services such as respite, family support, and speech therapy. In addition, children with a diagnosis also have access to autism-specific funding to assist with the cost of purchasing autism intervention services including communication, social-emotional, pre-academic and functional life skills development. Families of children under age 6 have access to \$22,000 per year and families of children age 6 through 18 have access to \$6,000 per year to purchase out of school services. This may sound like a lot, but on average a comprehensive early intervention program can cost as much as \$60,000 per year.

"It takes a village to raise a child with autism. We have to help families, but we also need to educate whole communities. The Pacific Autism Family Centre will leverage our resources, bringing all the threads of knowledge together. Then, through technology, outreach and dynamic exchange, we can get that information to every corner of the province in a timely, accessible fashion, developing a holistic set of approaches that are evidence based and proven effective."

**Dr. Karen Bopp
Ministry of Children and Family Development
Post Doctoral Fellow, UBC**

In BC once a diagnosis is confirmed families accessing autism funding programs must learn to navigate a complex and confusing system of therapies and supports, often with little or no guidance. How parents spend the money and what kinds of treatment protocols they choose are up to individual families: there are some guidelines in place but there is very little reliable, unbiased advice on how to design and structure a comprehensive treatment protocol. Few teachers, social workers and medical practitioners have any specialized training in autism and the wait to see specialists can be years long. A lot of parents are left surfing the internet, doing the best they can and trying to learn on their own.

Because Autism is such a complex disease with such diverse and far-reaching impacts, it's not something that can be addressed within the singular silos of medicine, education, research, psychology, or social work. That's why governments face such challenges conceptualizing how to develop an effective and integrated system to treat and manage it. Facing a possible \$60,000 in annual treatment costs, families early on are

extremely vulnerable to misinformation and those trying to sell them a "quick fix".

Desperate, they may spend tens of thousands of dollars of their own money on what seems a promising program, only to find out later that the person who sold it to them has no recognized credentials and that the program has no reliable evidence base whatsoever.

Many families lose their homes and go bankrupt in the process of trying to manage their child's care, and parents without resources are left in a situation in which their children can't get the full extent of care they need. Suicide rates among fathers of severely autistic children are as much as 15 percent, and up to 80 percent of marriages end in divorce.

As children grow into adolescents and adults, the situation becomes even more bleak. After age 19, there is virtually no support for adults transitioning to post-secondary education or the workforce or to assist them to manage their needs throughout their lifetime. While

"Can you imagine saying to a person who's just received a cancer diagnosis, 'Here, take this money. It may only cover about a third of what you need, but it's really up to you to determine what you need because there's really no reliable information available. Now, go and try to design a treatment program for yourself. Best of luck.'

It would sound ludicrous in the face of any other life-changing diagnosis, right? But basically, without a support centre like the PAFC to help them, that's what we're saying to these families every day. It would be like walking into a showroom to buy a car and the salesman sends you to the parts department and says, 'Build your own.' Well how on earth would you know how?"

Chris McIntosh

Autistic adult and PAFC steering committee member

Did You Know?

- **Studies have shown that among identical twins, if one child has an ASD, the other is affected 36 to 95 percent of the time. In non-identical twins, if one child has an ASD, the other is affected 0 to 31 percent of the time.**
- **Parents who have a child with ASD have a 2 to 18 percent chance of having a second child who is affected.**
- **About 10 percent of children with autism are also identified as having Down syndrome, fragile X syndrome, and other genetic and chromosomal disorders.**
- **The majority (62 percent) of children with ASDs do not have intellectual disability.**
- **Most children are not diagnosed until age 3 or 4; yet research has shown that a diagnosis at age 2 can be reliable, valid and stable.**

many with milder forms of autism, like Asperger's, go on to successful lives and careers, those with more serious impairments can end up living on the streets or in group homes and single room occupancy hotels.

A Tragedy for BC Families

This is truly a tragedy because today there are many treatments available for autism. People on the Spectrum often have very high potential to develop their skills and lead productive lives, and many are capable of making extraordinary creative contributions to their communities.

At present, the most commonly accepted treatments for autism are based on the theory of Applied Behavioural Analysis, a model in which specially trained caregivers may spend as much as 40 hours per week with a child, gradually coaxing them to modify behaviours and build learning and functional skills. A scientific method to learning, the techniques consist of an intensive behavioral intervention which is carried out early in the development of children. It involves breaking skills down into their most basic components, rewarding positive performance with praise and reinforcers, and then "generalizing" skills to real-life situations. By implementing the intervention for 20 to 40 hours a week, children can gain language, academic and basic living skills. Some estimates state that up to 90% percent of children on the spectrum have been shown to positively respond to interventions based on ABA, and as many as 47% can go on to live normal, productive lives.

Specialists trained in the theory of ABA and the specific treatment approaches that embrace this model are hard to find. Because ABA has only been available in BC for the past 8 years, there's a huge shortage of qualified practitioners. Today, there are more than 8,500 children needing services in British Columbia and only a few hundred properly qualified specialists trying to serve them.

Believing in Our Potential

There are no easy answers to solving the autism puzzle. But in BC, a creative community of parents, donors, scientists, and clinicians have spent the last few years exploring the following question: what is the single most catalytic and impactful thing our province could do to proactively address the autism problem and to provide immediate support to families? The answer: a new kind of multidisciplinary resource centre capable of harnessing, evaluating and disseminating the body of reliable evidence to date, addressing critical gaps

in the system and launching new programs and research designed to deliver practical, implementable clinical, educational and social solutions.

Pacific Autism Family Centre will be a special kind of interdisciplinary organization that will be the first of its kind in the world. In addition to being a safe harbour for families at the outset of their journeys with autism, it will work to harness the right expertise, the right people, and the right educational programming

necessary to develop clinically proven strategies, tools and solutions that can be easily disseminated and communicated to communities, families and schools throughout the province.

With more than \$20 million committed by the province of BC, the Pacific Autism Family Foundation's **Futures** Campaign is poised for the realization of a resource so unique, so impactful and so forward-thinking, it stands to become a global model for how communities everywhere will one day think about, manage and address the autism crisis.

A Centre Unlike any Other

A magnificent, 60,000-square-foot building, it will be specifically designed to meet the unique needs of children. Calming, family-friendly spaces with soft lighting will house clinics, labs, school classrooms, observation rooms, multidisciplinary research spaces, libraries, and family information kiosks will sit alongside spaces designed to provide new homes for some of BC's most prominent and proven non-profit autism organizations working across the province.

"All my life, my mom and dad tried to figure out how to help me. Little things like dimming the lights or letting me get out of the classroom before the bell went off helped me so much in school, but hardly any teachers have training in this, so they don't know.

Thanks to my family and a lot of people who cared about me, we found out what worked. I'm in college now, and I am even helping my school out with managing their computer system. I am nervous about making the transition to the workforce, but with the PAFC, I could get some help with that.

It would be great to have a place to go where I could be among friends Maybe there are 4 to 5 guys like me working together to make the transition so it's not so scary."

**Lucas
Teenager with Autism**

Improving the way all parts of BC's autism community interact and support families is at the heart of the concept. As such, a primary priority of the PAFC, both architecturally and philosophically, is to create an environment

purpose-built to facilitate the continued cross-pollination of new thinking and ideas. This way of working will not only help provide a "one-stop-shop" for desperate families looking for support and to navigate a sea of information, it will also lead to new ideas, better solutions and streams of research that may never have come to light with families and specialists working in isolation.

The PAFC will be a home for families, researchers, fundraisers, teachers, medical students, governments, educational assistants, social workers, psychologists, and people on the spectrum to gain a sense that new solutions are within our grasp and that people with autism and their families comprise a large and growing community. In addition to state-of-the-art clinics, wired classrooms and lecture theatres, accommodations for visiting families, distance learning

programs and offices designed to effectively accommodate a massive outreach effort, there will be open, light-filled common spaces designed to create the atmosphere of a little town, "learning village" or hub – places for informal exchange, dialogue and support that currently don't exist in any other kind of venue.

"The prevalence of autism is accelerating at an alarming rate. In 1975, just 1 in 2,500 children were getting diagnosed. Today, it's less than 1 in 100.

The next set of solutions will be at the convergence of a wide variety of disciplines and include families, communities and a wide range of thinkers. No one group can do this alone. Communities, schools, health care systems, and governments must work together."

**Dr. Glen Davies
Founder, ABLE Clinics**

"When our son failed to respond to our voices as a toddler, we thought he was deaf at first. But then we saw that when he heard certain noises, his head snapped. He wasn't deaf; it was something else.

At first, we didn't want to buy into the diagnosis. People said, 'Oh, he's just a little slow.' But you quickly realize the magnitude of what you're facing, and then you need somewhere to turn. That first 100 days was so frightening. From that moment on, you're running a small business – with consultants, caretakers, educators in and out every day. You don't know where to find the resources. The PAFC will be a softer place to land for families as they enter the world of Autism Spectrum Disorder. It would have been such a relief to have someone who could help put the pieces together and help us avoid making some pretty big mistakes."

**John
Parent**

Fusing truly individualized “person-centred” humanistic values with the best of what technology and large-scale research endeavours can offer, the PAFC will represent a truly new vision for treating and managing autism in our province, as families, governments, healthcare, education, and the community come together to link research, teaching and direct care. Right now, especially for families in remote parts of the province, there are just not enough specialized resources available locally to help them.

“The PAFC is not about bricks and mortar. It’s about building a foundation to explore undiscovered territory in addressing the needs of people with ASD and their families in a way that has previously not been possible. As a true aggregator of information, it will be a kind of ‘big bang’ for advancing the autism agenda in the province.”

**Dr. Pat Mirenda,
Professor, Special Education, UBC**

Now, they have a place to go for reliable information and help, no matter where they live. And if they can’t come to us, the PAFC will go to them, by making use of an outstanding network of strong technology platforms, information-sharing broadcasts and distance learning programs, and outreach interventions and workshops delivered in patients’ home communities. The PAFC will also partner with communities across the province to create ‘satellite’

“Twenty years ago, the situation for parents was bleak, to say the least. When I realized my son was affected, there was almost nothing available for me. Before it was on the DSM-IV, many doctors had never heard of it. People with autism were labelled as retarded, and some were unnecessarily institutionalized.

I persisted on my own. I learned. I did painstaking research. I found out what worked for my son, and now he’s completed school, has a driver’s licence and has a shot at a bright future. We have something here we can do something about. Hope and help are available, but early diagnosis is key. We need to make that information available to parents today, before their children lose valuable time.”

**Betty Anne Garrick, Parent
Co-ordinator, Autism Kamloops**

locations joined to the Richmond facility through a hub-and-spoke model. It is anticipated this model will provide more efficient and effective ways to link the province’s resource base into a seamless whole, linking families efficiently with the resources they need in their community and helping to reduce duplication in services. A current serious problem facing the autism world is the fact that there is just not the sufficient critical mass in disparate parts of the province to provide an effective clinical environment in which current and future professionals can learn. Over time, the Centre and its satellite operations will play a key role in educating more teachers, teaching aides, ABA specialists, medical and nursing students, psychologists, social workers, speech pathologists, occupational therapists, researchers, and

caretakers by providing exposure to workshops and practicum experiences with individuals on the spectrum.

Conclusion The PAFC will be the first organization of its kind dedicated to knowledge

creation and knowledge translation that will target applied models that can easily be shared and disseminated to families on the ground. In so doing, it will be a place that will attract a whole new generation of thinkers and researchers – people who want to design actual clinical programs, but who, up until now, have not had access to the critical mass of subjects, families and interdisciplinary co-researchers to do it. With the establishment of a hub like this, we have the chance to be better able to see, track and examine patterns – to look at similar groups and test approaches that may have been identified in isolated cases and can now be applied to a broader demographic.

“The PAFC will be a kind of ‘MAYO Clinic’ for researchers. It will be a place where researchers and clinicians have the opportunity to come together in a multidisciplinary environment and share their findings on a daily basis with individuals and families. Through the dynamic interplay of research, clinical care and ongoing dialogue, our knowledge base and approaches will evolve constantly, helping to ensure that BC families are always abreast of the very latest evidence-based approaches, as well as having access to the informal knowledge networks that come from being in touch with other families in similar circumstances.”

Dr. Suzanne Lewis, Senior Clinician Scientist, CFRI

Donors to the Pacific Autism Family Centre will be true visionaries, helping to stake out new frontiers in 21st century healthcare, education, social justice, and social innovation. In addition to building a lifeline for families, they will also be impacting every aspect of society and community, with provincial, national and, in time, global impact.

Autism is emerging as one of the most pressing issues of our times. The Pacific Autism Family Centre is a once-in-history chance for British Columbia to leverage our excellence on behalf of BC families, communities throughout Canada and – increasingly – people all over the world. For a relatively modest investment of \$13 million, today’s donors will have an unprecedented opportunity to have an immediate impact on children and families today and to see that impact resonate for generations into the future. As an inaugural donor to the **Futures** campaign, you can rest assured that the future will be different because of what you do.



GIFT NAMING OPPORTUNITIES DESCRIPTION

Naming of the Building

A legacy opportunity for a visionary, to be part of where the history of Autism Spectrum Disorder will be rewritten and the lives of thousands of British Columbians changed forever.

Treatment Centre

The Centre will provide treatment services to children and families through a fully integrated pre-school and after school program. The space includes classrooms, assessment, activity and observation rooms, meeting and family rooms, administration support, offices for specialists, and sensory and calm spaces.

Clinic & Research Centre

***The Clinic** will provide medical and psychological assessments; and opportunities for visiting medical professionals to provide treatment in the Centre. **The Research Centre** will provide applied research opportunities for a variety of professionals working with autism and related disorders through integration of all Centre components. Located on the second floor the space includes observation and assessment rooms, a laboratory, work spaces for researchers, family meeting rooms and a reception area.*

Entry Hall & Reception

Located on the main floor, this area will be the main point of contact for families and individuals visiting the PAFC.

Library & Learning Centre

The Library and Learning Centre will be an important resource for individuals and families to seek and share information on ASD and related disorders.

Lifespan Centre

Designed for youths and adults, the Centre includes classrooms, a computer lab, lounge areas and counsellor offices. The need for specialized vocational training, life skills and assistance with post- secondary education is fundamental in maximizing individual potential and achieving meaningful inclusion in the community.



Leadership Centre

Located on the third floor this is an area designed for the Executive Director and staff that will play a leadership role and features offices, shared meeting spaces and a state-of-the-art Boardroom.

Auditorium

A multi-purpose room with the capacity to seat 200 people, it features a fold away acoustic partition to accommodate larger or smaller groups in an auditorium setting or as a meeting room.

Research Library – Atrium

The impressive atrium area is the architectural centerpiece of the Centre.

Secured Outdoor Play space

This space is located outside the Treatment Centre for young children to play in a secure and supervised environment.

Life Skills Classrooms

These classrooms will facilitate the teaching of life and social skills support and training, banking and financial planning, grocery shopping, everyday life skills that promote independence and inclusion in the community.

Activity Room

These rooms located in the Treatment Centre will be utilized by children attending the Centre and will include art and music rooms.

Computer Classroom

Located in the Lifespan Centre this classroom is designed to teach educational and social computer skills to youth and adults.

Classrooms in Treatment Centre

The classrooms will be part of a fully integrated pre-school and after school program for children.

Outdoor Garden (including covered patio)

A tranquil space where families and individuals can congregate outdoors in a secure and peaceful environment.



Satellite offices

Serving the entire province is an essential feature of the PAFC and these regional offices are the “spokes” of the Centre and will be located in communities across B.C. They will range in size and will be part of existing buildings. The offices will provide space for video conferencing, meetings and a quiet room.

Laboratory

Located in the Clinic and Research Area, the lab will be accessible to a variety of medical and research professionals to conduct important research on autism and related disorders.

Music Room

Located in the Treatment Centre, the music room will have a piano and a variety of instruments for children and youth to be exposed to and learn the beauty of music.

Medical Assessment/examination rooms

These rooms are part of the Clinic and Research Centre and will be used for diagnosis and assessment.

Main Board Room

The state-of-the-art Board room located on the third floor will be used by PAFC leadership and partners within the Centre (seats 16).

Parents', Youth and Family Waiting Rooms

All the waiting rooms are designed to provide comfort for those on all parts of the ASD spectrum and to assist with creating positive experiences for individuals and families visiting the PAFC.

Calming or Sensory Rooms

Calming rooms throughout the facility include soft enfolding furnishings and will have the ability to be adapted to suit the sensory needs of the occupants.



Catalyst Endowments

Ensuring that the Pacific Autism Family Centre is positioned for long-term sustainability and that it is poised to move quickly to fill current service gaps is at the heart of the establishment of the PAFC catalyst endowment funds.

These named endowments, established in perpetuity, will enable donors to become partners and co-creators, helping to build the Centre across a range of dimensions. Catalyst endowments will provide seed funding to launch new Centre initiatives, providing the means to launch or design new program concepts. In many cases, the endowments will play a critical role in inspiring matching funds or launching innovative partnerships within many vitally needed areas of focus.

- **Leadership and Innovation**
 - *(e.g., Research; Demonstration sites; Training; Mentorships; Navigator Program)*
- **Children and Youth** (Treatment and support)
 - *(e.g., bullying education; evaluation of promising practices – validity in the community setting; knowledge translation; etc.)*
- **Transitions**
 - *(e.g., transitions throughout childhood – preschool to school; school to high school; first job, etc. Plus a strong focus on successful transitions to adulthood)*
- **Adult Programming**
 - *(e.g., Job Coaching; Vocational Training; Life Skills Support; Quality of Life Services; etc.)*
- **Technology**
 - *(e.g., connecting families; service providers; community support workers; researchers, etc.)*
- **Social Justice**
 - *(e.g., street youth; education for first responders; etc.)*
- **Family**
 - *(sibling support; Family-to-Family Connections; Support Groups; Recreation Opportunities; etc.)*

