# TWENTY YEARS AT THE FASD NETWORK

### 1995

#### The Network is registered as a non-profit.

In 1993, the Saskatchewan Institute on Prevention of Handicaps hosted a provincial symposium on Fetal Alcohol Syndrome in Saskatoon, Saskatchewan. A group of parents and caregivers of individuals with fetal alcohol spectrum disorder (FASD) connected at the symposium in recognition of the need for parent support.

The peer support group was helpful, but it soon became apparent that external support was necessary. There was an obvious absence of services and supports to individuals and families affected by FASD.

In 1995, the Saskatchewan Fetal Alcohol Support Network became incorporated. At that time, the group performed a needs assessment to determine common areas of concern and future direction.

### 1998

#### 'Living with FASD' is published.

In 1997, the Network submitted a proposal and obtained a grant from the Saskatchewan Government and the Saskatchewan Institute on Prevention of Handicaps to publish a provincial newsletter.

The Network was pleased to present their premiere issue of the provincial newsletter, originally entitled 'Living with FAS/E,' in 1998. The project was taken on by Robin Smith along with support from the Network Board of Directors.

At that time, FASD had only recently been acknowledged and was underfunded and underserved. The intent of the newsletter was to connect individuals and agencies across Saskatchewan who share a common interest in issues surrounding FASD.

Articles included information on the disability, strategies for care providers, reviews of resources and available services, as well as updates on projects and programs operating within Saskatchewan.

The first volume of the newsletter offered three issues throughout the year. Since its start in 1998, 30 editions of 'Living with FASD' have been published.

### 2002

#### The Network receives its first funding.

In 2002, Shelley Kolisnek submitted the first funding application to Health Canada on behalf of the Network.

In January 2002, the organization received the Health Canada Project grant. The grant enabled the organization to rent office space in Saskatoon, hire a part-time employee, attend conferences, and prepare new resources for Saskatchewan.

The success of this project was due not only to the financial support of Health Canada but also to the more than 700 volunteer hours put in by Board members during the time frame of this project and the dedicated staff member that was hired, Michelle Stromberg.

## 2002

#### The Network attains charitable status.

On May 4, the Network received chartiable status. This allowed it to start offering receipts for charitable donations and was one of the first steps to becoming recognized across the province as an official organization.

## **2002** Toll-free support line is created.

On Nov. 1, 2002, the Network set up a toll-free line that worked across Canada to better meet the requests coming in. The line received 179 calls from Nov. 1, 2002 to March 25, 2003.

Today, the Network is still running the toll-free line. Families and individuals experiencing a tough time can phone in to receive advice from the Network's support workers.

### Official website is launched.

As the Network advanced, so did the times. In 2003, the Network arranged for the development of a website that would provide basic information about its work.

"It's important that we have a presence on the World Wide Web," said Marion Tudor, who was president at that time.

The site was made possible through a grant from Health Canada's Prenatal Nutrition Program. An online presence gave the Network yet another way of communicating with parents and professionals.

In 2005, an updated website was launched. This website was easy to update from the office and had become a wonderful communication tool for the organization.

#### Speakers' Bureau partnership is formed.

The Network partnered with the Saskatchewan Institute on Prevention of Handicaps (now known as the Saskatchewan Prevention Institute) to create the Speakers' Bureau.

With funding provided by Health Canada, this partnership was able to train 12 individuals as Speakers' Bureau members from seven communities across the province. The Speakers' Bureau members were trained to deliver FASD presentations in their communities.

It was a very successful endeavour, and there was excitement about maintaining and developing this initiative. In the 2005/06 fiscal year, the Speaker's Bureau members delivered 63 presentations in 20 communities reaching over 1,900 people.

In March 2014, the Speakers' Bureau included 30 trained speakers.

In 2015, the Network created its own training model, 'Train the Trainer,' to deliver training to frontline staff who work with individuals living with FASD.

### 2004

#### First stable funding is received.

In March 2004, the Provincial Government provided the Network's first stable funding, as part of their Cognitive Disability Strategy. This was in part thanks to Marion Tudor and Shirley and Terry Hellquist's meeting with the Minister of Social Services, Glenn Hagel, in Regina.

The organization had received short-term and project funding from several other departments and agencies throughout time, but this was the first stable funding provided.

The funding was much appreciated and used to continue the hard work and stay focused on the vision of the Network.

### 2005

#### The Network's name is changed.

On Jan. 29, the Saskatchewan Fetal Alcohol Support Network changed its name to the FASD Support Network of Saskatchewan.

As research revealed more information around the disability, the diagnosis criteria had changed. In 2005, the Board of Directors moved to change the organization's name to keep in line with the current terminology of the disability.

At this meeting, the vision statement was also revised. It was moved that the vision statement now read: The vision of the Saskatchewan FASD Support Network, a parent-led organization, is for individuals with Fetal Alcohol Spectrum Disorder and their families to recognize themselves as safe, supported, valued and contributing members of the community.

As the Network continued to work toward its vision and mission, the organization noticed a growing need for education and training. To ensure the Network could continue to expand and offer a variety of services, the Board of Directors decided to remove the word 'Support' from the name. Thus, in 2014, the organization again changed its name. It is now known as the FASD Network of Saskatchewan.

### 2005

#### First Executive Director is hired.

The Network had been successful in receiving funding for a variety of projects. It was becoming more and more of a challenge for Board members, most of whom were parenting children or adults with FASD, to manage the projects, support families and individuals, and continue to look for

After a year of exciting progress for the Network, it was apparent that the Board needed support in order to continue its work as an organization. It was decided during the 2004/2005 fiscal year that it was time to hire an executive director for the organization. In March 2005, the Network hired Angela Schmolke as the first executive director.

Angela's outstanding dedication and commitment to the Network's vision of supporting individuals affected by FASD and their families and circles of supports was greatly appreciated.

### 2005

#### Post-secondary project is launched.

The Saskatchewan Liquor and Gaming Authority (SLGA) provided funding in 2005 to the organization. The funding allowed for a project to be completed, entitled "Prevention and Awareness for Post-Secondary Students about FASD."

This project included reaching out to post-secondary classrooms and providing FASD education presentations. Any field of study that would potentially be working with individuals with the disability in the future were targeted.

In its first year, the project delivered 20 sessions which included over 500 students.

### 2007

#### Parent Retreat is held for the first time.

In 2007, the Network announced that planning was in the works for an exciting parent workshop. The event would be for parents and caregivers and would include plenty of opportunities for learning new information while connecting with other parents and caregivers.

The first parent retreat, hosted by the Network in the fall of that year, was envisioned as time away from the multiple responsibilities, tasks, stresses and routines of everyday life. The organization wanted parents and caregivers of individuals with FASD to feel that this was time set aside just for them to be with others who might understand their experiences.

When the Network sent out the invitations to the first-ever retreat, they were cautiously optimistic. "We hoped that parents and caregivers would see the value in this gathering and want to come, but we were unsure as we had not tried an event like this before."

Very quickly, emails, faxes, phone calls and letters came into the office. Evidently parents and caregivers were interested.

As a way to help parents and caregivers feel special and pampered, a massage therapist was on site, meals and hotel accommodations were provided and fabulous door prizes were presented.

In addition to all the mentioned comforts, the organization arranged several excellent presenters and performers including Dr. Patricia Blakely and Krystle Pederson. There was a blend of practical information, fun and pleasure.

### 2007

#### Awareness Guide is created.

One of the primary goals of the Network has always been to educate community members about FASD.

In 2007, the organization was providing education through workshops, presentations, its website, and by mailing out information packages on request. The Network was proud to provide quality education to individuals and groups throughout the province and across Canada.

In that same year, the organization recognized the various needs for different information and produced a booklet in which all of the useful information on FASD was gathered.

The booklet was titled 'Fetal Alcohol Spectrum Disorder: A Guide to Awareness and Understanding.' This booklet brought together a collection of information sheets and articles along with the entire set of '20 FASD Tips for Parents and Caregivers' that had been created over the last 12 years.

The response was incredibly positive. The information contained was suitable for families, professionals, support personnel and the general public.

Today, the Awareness Guide remains one of the organization's most popular resources.

### 2008

#### Sunflower logo is developed.

In the Winter 1999 issue of 'Living with FASD,' the Network staff began their hunt for logo ideas, reaching out to the members to submit their designs.

As they learned more about FASD and grew as an organization, they found a common interest in the image of a sunflower. The sunflower is symbolic, not only of the vision and activities of the Network, but also of the many infants, children, adults and families living with FASD throughout the province.

Years later, as a more established organization, the Network continued to call on the symbolic power of the sunflower. It used the sunflower, a hardy, cheerful plant, to enhance its visual identity and raise its community profile. Sunflowers adorned print materials and inspired people in countless ways.

The organization encouraged individuals to consider what we have learned from the sunflowers that seem to dance in the Saskatchewan winds and face the brilliant sun with courage, even on the hottest, driest of summer days.

Marvel at the resilience of the sunflower that takes the opportunity to thrive.

As the organization grew alongside the community, the need for inspiration and sense of hope from the sunflower remained vital.

In 2008, the Network decided to make the sunflower its permanent logo. Since then, the sunflower logo has been used to help with the organization's visual identity.

### 2009

#### Foster parent training is mandated.

In the Fall of 2009, Sandy Overs and Marion Tudor visited the Post-Adoption Training and Standards team in the Regina's Social Services office.

This meeting resulted in an agreement that the Network would partner with the Ministry to create and facilitate a three hour mandatory training module on FASD.

The Network retained authority over the content and delivery method of the training, and put the FASD Provincial Speakers' Bureau to good use in its delivery.

The Ministry in turn offered its support by co-ordinating the workshops in communities across the province beginning in the fall of 2011, and ensuring that all foster parents are trained by the Network.

## 2011

### Family Support Program is piloted.

The Family Support Program project was accepted by the Ministry of Health (Cognitive Disability Strategy) thanks to a position paper developed in partnership with the Self-Directed Support (SDS) Advisory Committee.

The SDS Advisory Committee had been working diligently to develop a position paper to provide to government indicating that more adequate and broad options needed to be provided to families and individuals with disabilities in Saskatchewan.

In 2011, the Family Support pilot project was underway, and an amended proposal to Saskatchewan Health had been submitted. Two Family Support Worker positions were soon filled.

Today, the Support Program has expanded to a fourperson team, including a Support Program supervisor, that aims to work with families and circles of support to gain positive outcomes for those living with FASD.

The program offers support through one-on-one case management, the toll-free phone line, monthly support meetings and online communities.

### 2015

### Network launches new visual identity.

Since its incorporation in 1995, the Network has experienced tremendous growth. To reflect this growth and represent its new, extended services, the Network decided to rebrand the organization.

The initial purpose of this strategic change was to create a meaningful and cohesive brand that allows the Network to continue expanding its services while being represented as a professional and contemporary organization.

In preparation for creating a new visual identity, the Network contacted current and past stakeholders to gain a better sense of their perceptions and feelings toward the organization. The Network gained an overwhelming response of positive feedback. Individuals

and communities across the province expressed their appreciation and gratitude for the services provided by the Network over the last 20 years.

To maintain continuity with the visual identity developed throughout the history of the organization, the new logo was designed as a modernized version of the sunflower. Elements of the flower are still incorporated in recognition of the organization's past and all those who worked to establish the FASD Network of Saskatchewan as a prominent, provincial organization.

Along with the newly developed logo, the Network's staff worked towards recreating the print and online resources offered by the organization. With a new look and updated information, the Network is as committed as ever to providing Saskatchewan with educational material on FASD. The new resources can be viewed at www.saskfasdnetwork.ca

#### The next twenty years...

Although the current Network may not be recognizable as the small group of parents who started it in 1995, the values of this organization originate from that first meeting. The spirit and determination of those caregivers will forever be the foundation of the Network.

It was their vision and hard work that allowed the Network to support and educate so many people throughout the years. It was their unwillingness to let the lack of services continue, their endless volunteer hours, their relentless pursuit of funding, and their incredible ability to care for their own families while supporting others that led to the last 20 years of success.

Now, in 2015, the future of the organization is bright. FASD is more prominent in the minds of the public; general awareness and understanding of the disability has increased throughout the province. The Network will continue to foster this growth through training and support.

The staff at the Network are committed to fulfilling the vision laid out by our founders, 'for individuals with Fetal Alcohol Spectrum Disorder and their families to recognize themselves as safe, supported, valued and contributing members of the community.' The lives of so many individuals and their families are immeasurably better thanks to the work of the Network's past staff and board members. Those of us currently continuing work at the Network would like to thank them for their passion and their vision.

We share the great privilege and responsibility of carrying this legacy into the next 20 years.

#### The FASD Network's Boards of Directors

1997/1998:
President:
Jonina Male
Diane Wells
Dorothy Reid
Ina Mae Collins
Joyce Westfield
Sharon Taylor
Valerie Lawson

1998/1999:
President:
Jonina Male
Diane Wells
Dorothy Reid
Ina Mae Collins
Joyce Westfield
Sharon Taylor
Valerie Lawson

1999/2000:
President:
Jonina Male
Cindy Lee
Dorothy Reid
Harold Steppuhn
Ina Mae Collins
Joyce Westfield
Sharon Taylor
Shirley Hellquist
Sue Steppuhn
Terry Hellquist

2000/2001:
President:
Jonina Male
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Harold Steppuhn
Ina Mae Collins
Joyce Westfield
Sharon Taylor
Shirley Hellquist

Shelley Kolisnek Sue Steppuhn Terry Hellquist

2001/2002:
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Shirley Hellquist
Terry Hellquist

2002/2003:
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Trudy Shingoose

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Marion Tudor
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Sylvia Nagy
Terry Hellquist
Tracy Breher

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Sandy Overs
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Sandy Overs
Sharon Taylor
Shirley Hellquist

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Shirley Hellquist
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Lesia Gawryliuk
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