

The **Irish Times** of Tuesday, September, 2016, printed 21 faces of young children with Down Syndrome. **The Down Syndrome Center's 21 Faces** campaign is about inviting the viewer to take a second look. Down Syndrome is something some children are born with but it is not who they are. Dublin Bus has also supported the campaign by displaying 500 posters on its buses. Even more posters are visible around Dublin city. And there are many questions we could ask parents. Here are four testimonials.

Simon Smyth: Testimonial by his mum, Rebecca Sweeney Smyth

On May 19th, 2013, our lives changed forever with the arrival of our first child, our beautiful son Simon who had been prenatally diagnosed with Down Syndrome 10 days previously. We were plunged into the unexpected - this wasn't the plan. Consumed with grief, fear, and worry, I was very unsure of what the future would hold for me as his mother and the challenges we would face as a family.

Previous to Simon's birth, I had little knowledge of the difficulties people with Down Syndrome and their families experience. Issues such as low muscle tone which can cause feeding problems and delay reaching gross motor milestones, such as walking, as well as hearing difficulties and speech delays. I was unaware of the ongoing need for speech therapy, physiotherapy, occupational therapy and the many medical appointments needed to address medical issues that are common for people with Down Syndrome. These can include heart defects, thyroid problems, sleep apnoea, eyesight problems and more.

I had never heard of Lamh, which is a sign language used to help children with speech delay to communicate. I did not know that it was advisable for our family to learn and use Lamh in order for us to communicate with Simon and to give him a means to communicate with us. I didn't know of the struggle parents face to access an adequate amount of therapies through early intervention services, an area which is greatly under resourced. I was not aware of the financial pressures that are on parents to supplement the therapies privately.

However, neither did I realize how rewarding it would be to be a parent of a child with Down Syndrome and how, despite the difficulties, those initial feelings of loss, fear and anxiety would become less and less as time went by. I was determined from the beginning to do all I could to help Simon reach his full potential and to prove that, with the help of early intervention, people with Down Syndrome are as unique and diverse as the rest of society.

Archie Stanley: Testimonial by his mum, Nicola Smith

Archie! I have been writing and rewriting this, trying to tell you how strong Archie is and all he has overcome medically. However, I keep coming back to what's important and what I want to share with everyone. Now, now is what I want to tell everyone about. This unbelievably amazing moment we live in now that is our everyday life. Our everyday life is made extraordinary by one amazing little boy. This is the place we never thought we would be happy.

Archie wakes up every morning shouting Mammy, Dada, sometimes before the sun rises, and greets you with his big beautiful cheeky smile. The days when I worried I'd never hear him call for me have become a distant memory. When he walks into a room full of strangers, I watch him say hello or give a high five or again that cheeky smile. I watch the strangers' faces, how they are smiling from their hearts and their days have just been made better from a chance meeting with Archie.

I love the beautiful people he has made his sisters become. He has taught them patience and empathy and what it is to be yourself, to be unique. He has taught them to understand life and to just enjoy every moment. You see that's Archie. He has a way of making you feel happy. Blissfully happy. He makes life make sense. He does it all being himself.

Even his unbelievable infuriating stubbornness gives me a giggle because I know it's a personality trait he has inherited from me. His positive attitude to any obstacles he faces, he gets that from his dad. His craziness reminds me of his sister when she was his age and his laid back attitude to life is exactly the same as his other sister. You, that's what makes me happy, an everyday reminder that before any diagnosis, Archie is a person first. He is Archie and we adore every piece of him.

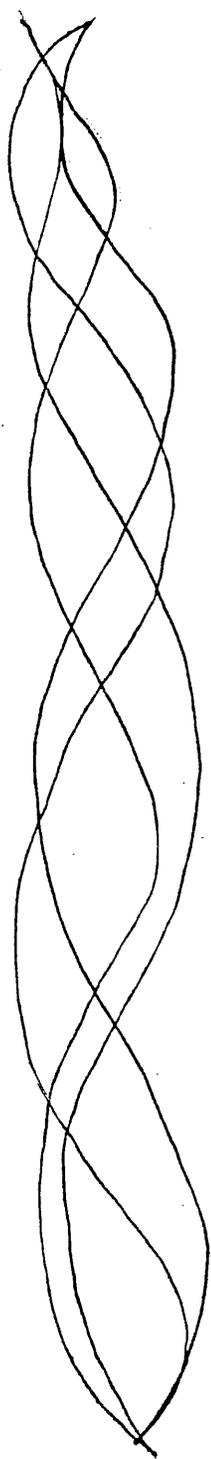
Lara Gilson: Testimonial by her mum, Jackie Carlile

When Lara was born, I cried a lot. Four years later I'm still crying. But now I'm crying tears of absolute love, joy, laughter and pride. Love, as I've witness her survive when the odds were medically stacked against her. Pride, as I've watched her overcome countless physical, intellectual, and social challenges. Lara has overcome challenges through her own determination and hard work, but also through the services she receives from the Down Syndrome Centre. The staff see Lara as I see her, a little girl with huge abilities rather than a condition of restrictions.

The benefits of Lara's occupational therapy are obvious as she balances and jumps during her local ballet class alongside her peers. She is pure joy to watch. So is listening to Lara telling her friends "knock knock" jokes. She always laughs loudly before the punch line. She has gained so much confidence and social skill. For me the most rewarding benefit has come from her speech therapy. I listen to my kind, intelligent, beautiful and funny daughter say "Mammy I love you". With tears of love and admiration, I reply, "Lara, I love you too, you're amazing."

Caoimhe McNally: Testimonial by her mum, Carina McNally

Caoimhe is an amazing, funny, determined, lovable little girl who is adored by her family and friends. She had a lot to overcome in her first few months - constant hospital admissions and eventually heart surgery at five months old - but she took it all in her stride. Since the surgery she



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has come on in bounds and now at 18 months, she has a mischievous little personality and loves to be in the thick of things at home, and is never happier than when she's dishing out hugs and kisses to anyone who happens to be around. She loves bath time with Aisling who is four, story time with Daniel who is six and play time with her cousins and cuddle time with mammy and daddy.

Thirteen weeks into pregnancy we were told that Caoimhe had Down Syndrome. We were terrified...we didn't know what the future held for her or for us or for her brother and sister, but she has brought so much to our family and has given us strength that we didn't know we had. She makes us smile every day. We're so thankful that we were chosen to be her mammy and daddy. From *Spred View*, Diocese of Armagh, Northern Ireland, Vol. 21, No. 9, December 2016, Editor, Patricia Lennon

Spred Chicago has also asked for contributions from parents who were asked "How do you feel when your child is in Spred"? Here is one parent's response.

Nadia Brogan: Testimonial by her mom, Bozena Brogan

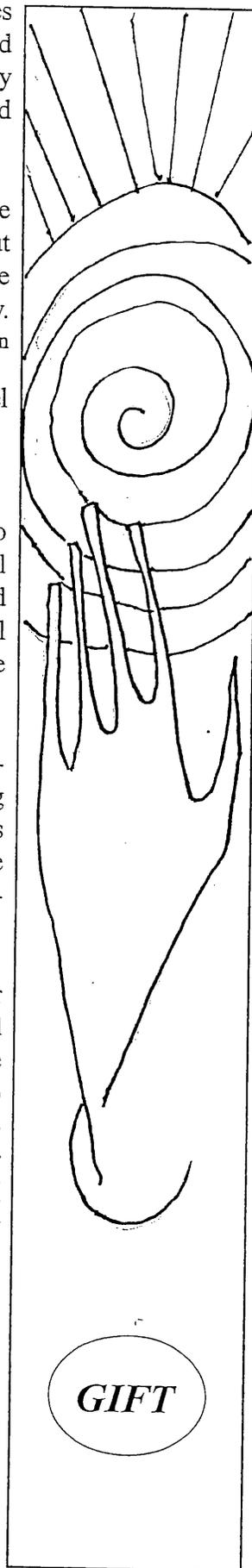
It was the song, the song in my head. First I started humming but later the words came. "I'm so glad that you're all here tonight, I'm so glad that you're all here tonight, I'm so glad that you're all here tonight, singing Glory, Alleluia, I'm so glad." This song is sung by everyone who can toward the end of the Spred session. Every time I hear it, I see happy faces. Our daughter, is not verbal so she can't talk or sing but in this moment she is "singing" and laughing like everybody else. She is happy.

At the beginning of the evening, when she arrives in the activity room, she is welcomed by everyone, the adults and other children. She explores the sand in the large container, painting, cutting and arranging flowers for the tables, making music with little music boxes. The room is always filled with soft, beautiful, classical music. These moments are even relaxing for me, sitting in the observation room, watching my beautiful daughter and everyone else through the one way viewing mirror.

Nobody is testing Nadia, nor teaching, nor grading her progress, nor having expectations, nor pushing her around. Everyone is just being with one another. After an hour the chairs are formed into a circle, everybody is waiting for the call to go into the mystery room, the sacred room, the celebration room. There they find a lighted candle, an open Bible, and the leader catechist who talks to everyone about simple things, about life, about something around us and inside us, memories from the past, the simple beauties of life, the smells and big things that God has made. After the little talk and some conversation the leader comes to each one and says: Jesus says to you, I am with you/ or Be with me/ or You are important to Me/ You are not alone..., something very close and personal. You can feel the presence of God, peace inside.

After this everyone enters the first room where it is time for a feast, agape time. Everyone is sharing in the preparation, bringing the dishes to each place, bringing the food to the tables, lighting the candles. These are happy moments with conversation, singing, laughing and eating. The sharing is not so much about each other but close, like one person to the other person, like brothers and sisters. Our daughter is not a good conversation partner but in Spred she is accepted for who she is, a beautiful human being, happy to come back again and again, and me, happy with peace in my heart. God is all around us, God is inside us. When we return home we are both still happy.

Sr.Mary Therese Harrington, Spred Chicago



CALENDAR

SPRED TRAINING

+2-1 Introduction to Spred English and Spanish

Spred Center Saturday Feb. 11,18,25, 1:00 to 6:00 pm
2956 South Lowe Ave, Chicago Il 60616, 312-842-1039

+3-1 Role Orientation, English and Spanish

Spred Center Saturday March 11,18, 2017 1:00 to 6:00pm
2956 South Lowe Ave, Chicago Il 60616, 312-842-1039

SPRED FAMILY LITURGIES SUNDAYS 11:00 am

Feb. 5, Mar. 5, April 2, May 7

OBSERVATION - Spred Center

6-10 Mon. 6 pm Feb.13, 27, March 13, 27
11-16 Tues.7 pm Feb. 14 28, March 28
22+ Mon. 7pm Feb.13, 27 March 27

SPRING MAMRE DINNER DANCE FUNDRAISER

Drury Lane, Oakbrook Sunday, April 23, 2017

CORE TEAM MORNING OF ENRICHMENT

Sat. January 28, 9:30 to 12:00 Spred Center 30th &Lowe
Chicago, enter through parking lot, go to third floor.
RSVP Elizabeth Sivek, 312-842-1039 ext. 13,donation \$3.00

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