... more than medical
Hi, I am Rebekah.

Whilst pregnant with my second child, whose Down syndrome was confirmed at 17 weeks gestation, I was provided with and was able to obtain an abundance of medical information about the condition; but nothing that gave me an insight into what life is really like for children with Down syndrome and their families which I so desperately wanted to know.

This booklet has been created to make information about the realities of family life with a baby, child or adult who has Down syndrome available to you.

It is a collaborative effort of individuals with Down syndrome, families who have a baby, child or adult with Down syndrome and Lose the Label, a community interest company dedicated to educating and updating social perspectives of the lives of children and adults who have Down syndrome.

If you are discussing a possible or confirmed diagnosis of Down syndrome for your baby I hope this booklet provides an insight about the realities, and family life.

Sometimes simply discussing your situation with someone else can be helpful.

Down Syndrome Ireland has a national office and 25 branches offering support and services, information and a listening ear for parents and families across Ireland.

In this booklet, you will come across some medical terms that you may not be familiar with. If you would like to find out more details of the various texts, checks, conditions and medical professionals you may come across in the lifetime of a loved one with Down syndrome, you will find it on downs syndrome.ie/health.

You can speak to Down Syndrome Ireland on 01 426 6500 or visit downs syndrome.ie.
Caoimhe

The moment Caoimhe was born I thought she looked different. The delivery room fell silent and there was very little congratulatory talk. I asked my husband to hold her so that I could see her. I knew straight away that she had Down syndrome.

We assumed that I wouldn’t be able to breastfeed her, that she would have heart problems, hearing and eye issues, walk late and have communication issues. We were wrong on all counts.

I asked if I could breastfeed her, just as I had my other children and somehow the familiarity of teaching her to latch on and nourishing her, made everything almost normal. I loved her from that moment. When her 8 year old brother saw her he asked if she had a disability, we said yes. That was that. Our other children accepted her and loved her.

The Challenges

The first year was filled with hospital appointments, physiotherapy, speech therapy, early intervention but each appointment ruled out a potential issue. The challenges of juggling Caoimhe’s needs and the needs of our other children were very real. There was ballet, hurling, gymnastics, soccer matches, homework. So Caoimhe was brought to ballet, and kept entertained on the sidelines by other siblings. Caoimhe has now started gymnastics herself.

The Medical

Caoimhe was born with a hole in her heart which closed after 4 years. She has annual hearing, visual and thyroid checks. In her early years Caoimhe regularly attended physiotherapy and occupational therapy but these appointments are less frequent now. She regularly attends speech and language therapy and is making great progress.

The Highlights

Caoimhe brings an extra dimension to life. Little things are big moments for her. She is full of love, affection and has a positive, simplistic outlook on life. I rush around her in a flurry, but we both get there in the end and she is usually in a calmer place than me.

Family Life

Family life is busy. Caoimhe has slotted right in and taught us things about ourselves that we didn’t know. My 10 year old daughter gave a presentation about Down syndrome in school today. She informed her classmates about chromosomes, time and patience but mostly about how much she loved her sister. They are excited to meet Caoimhe when she starts school next September and Caoimhe is very excited too.

Aislin and Paul
Parents to Conor 12, Eimear 10 and Caoimhe 4.
Sarah

We received Sarah’s diagnosis half an hour after she was born. We were devastated. Calling our parents to tell them their first grandchild had Down syndrome was the hardest phone call we ever had to make.

In the first few days and hours as a whole family we made assumptions about how Sarah’s life would progress. We assumed she would never go to the local school, she would never ride a bicycle and that she would not write.

Sarah has smashed our assumptions with her reality and our devastation has long since disappeared. She has just started junior infants in our local school, the same school her Daddy went to, and she loves it! Sarah has friends, she’s learning numbers, letters and even some Irish words.

The Challenges
We expect there will always be challenges at each stage of Sarah’s life. We are dedicated to do everything that we can to help her progress and become more independent. Tummy time was tough and learning to walk took a long time. Her communication and speech development was slow to progress. We supported her language development with Lárn, each new word was very special and a celebrated achievement, now she is a little chatter box.

The Medical
When Sarah was born she had to undergo an operation for a Duodenal Atresia, and she had further bowel surgery at two years old. Due to hearing problems she has also had two sets of grommets and is under the care of the ENT consultant. Overall her health is good.

The Highlights
There are numerous highlights to having Sarah in our lives; her infectious smile, her sense of fun and adventure and the way that she hugs those she loves. The most recent highlight was her first day at school!

Family Life
Sarah has a great relationship with her younger brother and is a very happy, confident and independent young lady. She loves being the centre of attention! Our family life is typical, we have two children and we just enjoy watching them grow up together with their unique and special bond.

Emma and Paul
Mammy and Daddy to Sarah 5 and James 4.
Céadan

Céadan was born in June of 2017. We were induced at 37 weeks due to Céadan measuring very small for his gestational age. Labour was very quick and 20 minutes after his birth we received his Down syndrome diagnosis.

I screamed, my partner David was dumbstruck – that lasted five minutes. We held him in our arms and the love was overwhelming. The need to protect him and help him be the best he can be was immediate. He is just our boy.

Our family was instantly accepting and supportive. He was our new baby, a new grandson, a new nephew, a new cousin. We embrace this new chapter in our lives.

“The Challenges
For us, the hardest part is the constant worry wondering what the future holds. There were appointments constantly for the first few weeks, they continue now but are not as frequent. Acquiring services is time consuming and can be frustrating and fitting the daily physio into a busy household is hard, but we are learning to manage it.

The Medical
Céadan spent six weeks in NICU due to low sugars, unrelated to his Down Syndrome. He has fluid in both ears and a conductive hearing loss – this seemed devastating at first but then our focus changed to how to help him make the most of the hearing he has. Céadan also has myopia in his eyes but so far, his sight is unaffected.

The Highlights
We are currently learning Lánn and teaching all our children; it’s really amazing to see how they pick it up. We have learned so much on this journey and we honestly wouldn’t change any of our children. For Céadan it’s the same, we worry about them all.

Family Life
We have four children, our little girl Maddy was the youngest at four when Céadan was born. Maddy and our two eldest children knew from day one he was just Céadan, their little brother and he has Down Syndrome. We have the same routine at home as we always did and life pretty much goes on as normal.

Vanessa and David
Parents to Megan 10, Clan 10, Maddy 5 and Céadan 1.

“Our family was instantly accepting and supportive. He was our new baby, a new grandson, a new nephew, a new cousin.”
Charlie

My name is Charlie
I am 22 years old and from Sandy Cove Co. Dublin

Education
I was so happy in school with my old friends Jazze and Kate. I liked computers, writing work and chatting about sports. I didn’t like hearing others cursing.
I completed secondary school on the ASDAN Programme.
I graduated from Latch-On*, a three year literacy through technology course and I am currently completing level 2 QAT Life Programme.

Interests
When I was young I remember playing soccer with my friends, chatting, playing games and eating potato waffles.
Now I like sports and business writing and spending time with my girlfriend.
I love my life, my work and want to marry my girlfriend.

Employment
I work at the creative agency, Irish International every Wednesday, it’s hard work but I love it. I am Deputy Facilities Manager at BBDO and my duties include checking the CCTV shredding, and delivering internal post.
I’d like to find work in an office watching CCTV cameras.

Family
My family are my Mum and Dad, they are really nice parents.
I have two brothers, Nancy my dog and Mirlam my girlfriend.
I feel confident, secure and I love my life, my family and my girlfriend.

*Latch-On forms part of Down Syndrome Ireland’s Ability Programme, which aims to provide people with Down syndrome access to meaningful employment opportunities.
Nathan

It was my husband who told me that our son had Down syndrome when he was born and when I looked at Nathan, I knew he was right. I felt very pampered and knew life had Changed forever. We didn’t really assume anything. I remember the Paediatrician asking me if I knew much about Down syndrome and went on to say that originally Nathan would not progress beyond the level of a 5 - 6 year old and I was so angry and disappointed with this old-fashioned view. Even at this stage, I remember thinking there was more to our child than this limited view.

My sense of humour saved me as there were some humorous moments in the hospital and there was a kindness too: the cleaner who said she would pray for us at 11 o’clock, the young nurse who came in during the night, sat with me and told me about her friend’s child with Down syndrome, and the nurse who helped me with breastfeeding.

Nathan is an extremely positive boy who embraces life and is very 'happy in his own skin'. He has brought great joy and fun to our lives.

The Challenges

Accessing services and knowing what assistance is available we found difficult along with the financial pressures due to reducing working hours in order to access therapies and classes for Nathan. Educating other people about language around disability sensitively and challenging those who underestimate Nathan’s ability along with developing a social life for him.

The Medical

Nathan did not have challenging medical conditions when he was born. He has a general medical every year or two and blood tests for thyroid. Nathan is long-sighted and he had the hearing tested this year, which is fine.

This highlights

A recent highlight was getting a special mention and standing ovation at his graduation ceremony from primary school. The Principal told me that the school community learned more from Nathan than he did from them. We’ve also had great holidays in Thailand, Africa and Europe.

Family Life

Nathan rules the roost at home and likes to hang out at home surrounded by his family. He loves to eat out for special occasions and welcomes visitors to the house with good manners, enthusiasm, and usually, a bit of dancing!

Gay and Married Seko

Hone and Dad to Nathan 13.
Lauren

Lauren was about an hour old when a consultant walked in, examined her, handed her back and then asked us if we “noticed anything different” with our daughter. Lauren was our first child and we had counted 10 fingers and toes and she had gorgeous big eyes and a full head of hair so, we hadn’t noticed anything different. The consultant then advised our daughter had Tricomy 21, not a phrase we were familiar with and eventually she said the words Down syndrome.

The internet became rather useful over the coming weeks as we learnt about the health issues Lauren may have and what she wouldn’t be able to do. In hindsight, we should have ignored the internet and just listened to parents, siblings and individuals with Down syndrome and got the real story… a far more complete experience.

The Challenges
The first few weeks were the most anxious as we went from one appointment to the next for her heart, hearing, eye sight, and physiotherapy. This and making sure Lauren was “in the system” was what we found the most challenging. Overall the first 2 years were full of appointments but for us since, it’s been more social and doctor engagements!

The Medical
Lauren wears glasses and hearing aids… purple with little sparkles. She had numerous holes in her heart from birth which all closed spontaneously by the time she was 4 years old. Lauren continues to attend physio and occupational therapy, along with speech and language therapy. 

The Highlights
Lauren is now 4. She is in Senior Infants in mainstream school and loves nearly every minute of it. One of Lauren’s greatest achievements was putting on her school uniform and heading off on her first day with all the other little girls… another step in her wonderful life, and so the play dates and birthday party circuit began.

Family Life
Lauren has two younger brothers, Cormac “tardy” four and Tadhg is 8 months old so life is very hectic for us all. Having siblings has been of huge benefit to Lauren… the house is always full of laughter and noise and we have no doubt that is not going to change any time soon!

Linda and Davy
Mummy and Daddy to Lauren 6, Cormac 3 and Tadgh 8 months.
Our initial thoughts when Emma was born were about her health, however she had no major health issues. We were emotional and concerned but just wanted to get on with life and do the best for Emma. We didn’t have any assumptions and just took each day as it came. We continued life as we did before Emma was born, keeping the everyday as typical as possible for our other two daughters. We were out and about a lot and went on some great family holidays. Emma loved being out and about.

The Challenges
The biggest challenge for us was helping Emma through secondary school, especially when her old friends started to move on from her socially, that was hard on Emma, and us.

The Medical
Emma’s health is excellent. She had chicken pox at the same time as her two older sisters and she has had the odd cold but nothing major.

The Highlights
We have had many, many highlights. Emma’s exam results, her swimming achievements and the concerts she’s taken part in.

Family life
We have a lovely family life with Emma, she loves going out and seeing new places and going abroad on holidays. Emma’s two older sisters have both left home and she misses them. Emma went on her own to visit them in London last Easter; she was very proud of herself for traveling alone and she had a great weekend.

Monica and Neil
Parents of Michelle 29, Karen 26 and Emma 20.
My name is Emma.
I'm 20 years old and from Ennis Co. Clare.

Education
I went to mainstream primary and secondary school in Ennis where I did my Junior Certification Exams in 10 subjects resulting with one A, two B's, 6 C's and two D's. I then went on to do the Leaving Certifed Applied Exam and achieved a distinction.

My secondary school was an all girls school and I had a part-time Special Needs Assistant. The worst thing about school was that I didn't have very many real friends, the best was my motivation to learn.

I go to Mary I College in Limerick 3 days a week where I'm doing a General Learning and Personal Development course, which is supported by the Brothers of Charity. I love going to College and spend the other two days studying and attending other interesting classes at the Brothers of Charity Centre in Ennis.

Interests
I am a member of Special Olympics Swimming Club and have qualified to represent Team South Galway in the All Ireland Finals in Dublin. I hope to learn how to play the violin in the future.
I played the violin when I was younger and now play the accordion and I'm a member of a Gospel Choir.

Employment
I'd like to work in music, acting and public speaking.

Family
I live at home with my Mum and Dad and love spending time with my Nana. I have two sisters who are older than me, Michelle is 29, Karen is 26 and they both work in London.
Jackson

When the doctor took my baby away saying he was ‘fussy’ I was petrified. Then when they came back and said he has Down syndrome I was sick with worry about his health. My Mum had previously lost a little boy with Down syndrome and I had so many questions. I finally held him a day later in SCU where he was being kept for close monitoring and testing.

Initially, I believed Jackson would never reach certain milestones, but the reality is that he’s so determined, he definitely gets there at his own pace and he has surprised us all with his amazing personality.

The Challenges
Jackson’s chromosome 14 had split which means he has Mosaic Down syndrome. I had to have genetic testing - my mind was a mess and I was scared. I then had to tell my whole family that they needed testing, which I found quite difficult - would they be angry, would they be scared? My Mum’s whole side turned out to be carriers.

Jackson is now 4, his speech is still developing and managing all the appointments with different service providers to get what he needs can be hard.

The Medical
Jackson got the all clear for his heart at 6 months old and that was a huge relief. He wears glasses and has pseudo-otos. He has had antibiotics and antacids. Sleep studies indicate he will likely benefit from having his tonsils removed.

The Highlights
Small triumphs are huge in our house. Jackson is hilarious and loves to sing, dance and is currently obsessed with WWE. His personality is infectious and he’s the most popular little boy.

Family Life
In our house there’s Jackson, his little sister Kara and his step-sister Clodagh along with me (Mammy) and Daddy. Jackson has shown so many of us that he is no different than any other child - he learns at a different pace but he’s taught us to let go and enjoy the little moments.

Leah and Keith
Mammy and Daddy to Jackson 4 and Kara 2; and Daddy to Clodagh 13.

Mosaic Down syndrome

1-2% of people with Down syndrome have a mosaic pattern. They have a mixture of cells with an extra chromosome 21 and some with the usual two cells. This mosaic of cells is caused by cell division after fertilization.

Some babies with mosaic Down syndrome may present with less of the physical characteristics typically associated with Down syndrome.
Eve

We found out our baby would have Down syndrome around 26 weeks into the pregnancy. We were devastated. We felt scared, sad, and fearful of the unknown. We also felt guilty that we felt this way. We assumed that our lives would never be the same, that our lives would be worse.

Eve looked just like her sister Faye when she was born. Nothing to be scared of!

Eve runs into pre-school each morning. She’s very much part of the gang and does what they do. She absolutely loves coloring, painting, gluing, play-doh and role-play. Eve is very sociable and full of fun. She is a bright little girl and takes everything in. She’s her own person and knows what she does and doesn’t want!

The Challenges

The first year was tough as Eve recovered from surgery and had feeding issues. There were a lot of appointments, arranging and chasing these was time consuming. Having the patience and belief that Eve will get there in her own time, be it with walking, talking and reaching milestones in general was challenging. I found it very difficult not to project too far in the future when Eve was a baby.

The Medical

At birth, Eve had Duodenal Atresia and surgery was required to remove the blockage in order for food to get to her stomach. Surgery was successful and Eve was home after 3 weeks. Eve had 3 small holes in her heart and a duct (PDA) that didn’t close. She was monitored by a cardiologist and over time all holes closed naturally. She had a day procedure to close the PDA and has had no further issues with her heart. Eve has fluid in her ears which the hope is will go as she grows, and she wears a bone conduction hearing aid.

The Highlights

After Eve’s first birthday things started to change for her. She could sit unaided giving her a new perspective and once she was burn shuffling her personality shine through, she developed physically and was more confident and outgoing. When Eve started using Lámh signs and saying some words, walking and just turning into the brilliant little 3 year old that she is.

Family Life

Eve loves to play with her sister Faye and with other kids. They have a great relationship and play, laugh and fight like any sisters. Eve enjoys watching Peppa Pig and the same TV shows as Faye, playing with their kitchen, garage and dollhouse. They both love books and having stories read to them. They really are more alike than different. Both girls love to go off with their Dad on his bike and we love going to the playground, out on their tricicloped, to the library, cinema, restaurants and on holidays. Eve is a much loved and respected member of our family. Her Down syndrome is part of our lives, but certainly doesn’t dominate it.

Carolyn and Carl
Parents of Faye 5 and Eve 3.
Sophie

Sophie and her twin brother Adam were born 10 weeks premature. On learning that Sophie has Down syndrome, I felt the only person who could understand what I was feeling was my husband because he was feeling it too. We were both scared of the unknown; I wondered if she'd walk or talk. I worried whether she'd be pretty like her older sister and if I even wanted if Laura (aged 5) would want her as her bridesmaid when she got married.

We assumed that Sophie would be the more difficult twin. Home from hospital after 8 weeks, Adam had to go back in with a chest infection. It was then that we decided to stop reading about what Sophie was expected to be like.

The reality was that having twins was really hard work. The fact that Sophie had Down syndrome hardly mattered for the first 5 months.

Gloria and Bernard,
Parents to Laura 21, Adam and Sophie 20.

"Any challenges have been ours, not Sophie's."

The Challenges
Any challenges have been ours, not Sophie’s. She was perfectly happy. Initially we worried about how she’d settle in school but she made friends and had plenty of play dates and party invites. Sophie went to a special secondary school where she had lead roles in the school plays, sang in the school choir and made great friends.

The Medical
Despite being 10 weeks premature, Sophie has always had great health. She has an underactive thyroid and is on daily medication for this.

The Highlights
In her younger years Sophie was in the local church choir, which involved singing at Sunday mass and also, doing readings and prayers. Because of this she has always been very competent at public speaking. The biggest celebration in Sophie’s life to date has been her graduation day from secondary school. There was a small ceremony and Sophie read a prayer followed by a formal speech about her time in the school.

It was such a special day for all the family. That same year, Sophie achieved a “B” grade in her Junior Cert Woodwork exam.

Family Life
Our family life is very typical. When Sophie was younger, her best friend was her twin brother Adam. Together with their other friend Aidelle, they invented great games and Sophie’s motto has always been “if Adam can do it then so can I”.

As they’ve gotten older they now have their own friends but still get along really well. Sophie has lots of friends whom she’s met through school and activities outside school and she meets them regularly though at the moment, usually accompanied by a parent.

We usually holiday in Inis Oirr with lots of cousins and because of this Sophie is great friends with all her cousins too. They’ve never given her special treatment so she’s always known about taking turns and sharing. They used to put on talent shows & plays and she has always been more confident than most at showing her stuff.

Sophie is now 20, witty, opinionated and well mannered. She is attending a 3-year Access Programme in the National Learning Network geared towards learning independent living skills in the community. She’s in her first year and seems to be really enjoying it. Sophie is the happiest, most self-contained person I know. She often tells me that she loves her life.
Jack

During my pregnancy we knew that our baby had a syndrome as there were many markers on scans and a significant cardiac defect to suggest it. I had almost lost him during pregnancy so we chose not to have any invasive tests, and we received his Down syndrome diagnosis at birth.

Jack was born two and a half weeks early and we were startled. The syndromes that we thought he would have were considered "incompatible with life" so we considered Down syndrome as a blessing. I had a traumatic emergency C-section and when my tine baby was born, he was whisked away and couldn’t feed. He was sent to the paediatric hospital the first night and I was terrified as they thought he had a further heart condition.

After two weeks in the maternity hospital learning to tube feed and attending CPR classes for parents, we took him home, for two weeks. He was then hospitalised for nine months.

The Challenges
Jack is severely to profoundly intellectually disabled, he is non-verbal and as he cannot stand or walk he uses a wheelchair. He needs 24 hour care and requires 13 different medications daily.

The Medical
Jack underwent two heart surgeries and many more procedures and surgeries. He was peg tube fed by 5 months old as surgery was needed to stop him aspirating as he had constant pneumonia and had been in ICU too many times with his little life hanging by a thread. The first 4 years were like this, and things only started to get better then.

Throughout all his hospitalisations Jack kept smiling and he was always plucky. We went to Great Ormond Street twice for two weeks at a time as he was very poorly on both occasions. A clinical diagnosis of an Auto Inflammatory Disease was confirmed, but not definitively.

The Highlights
My little boy is the light of our lives. Jack attends the most amazing special school, he loves it and adores his teachers. SNA, nurses and friends. We are lucky to have charities like The Jack & Jill Children’s Foundation, The Laura Lynn Hospice and Down Syndrome Ireland to help us.

Family Life
Overall Jack is a very happy little boy despite all his medical issues and many complex needs. Jack’s big sister adores him and he her. We love him and he enriches all of our lives. We wouldn’t change him for the world. He is a funny little character full of fun and mischief.

Aiming
Parent to Molly 14 and Jack 12.
Stephen

My name is Stephen but my friends and sister call me Foley. I’m 26 years old and live in Ballybogher in Kerry.

Education
I went to Nemo N Gaeil in Listowel. There were six in my class and all have Down syndrome, 3 boys and 3 girls. I loved acting and dancing and doing shows like Cinderella, Jack and the Beanstalks and Scrooge. I didn’t like writing and the maths was hard for me.

I’m currently at College learning about creativity in the community and politics.

Interests
I like College. I like writing. I go on trips with my mother to Kildare and Dublin to see shows at the 3 Arena and I like my politics course NOTE*: “My Opinion My Vote”.

Employment
I work in a book shop, a garden centre, and at St John of Gods. I love working in the garden centre because I love being outside with nature and working with wood. I work Mondays, Tuesdays, Wednesdays and Saturdays. I like all my jobs because I meet people and get paid for it. I’d really like a full time job working in an office for the Student Union.

Family
My mother and father live with me. I have two sisters and one brother. I am the youngest and I have the best mother in the world. I used to sing in the choir with my mother at church.

*NOTE: This part of Down syndrome Ireland’s Ability Programme, which aims to provide people with Down syndrome access to meaningful employment opportunities.
Conor had an emergency landing in September of 2003 at less than 4 lbs and with a life-threatening heart condition called "Tetralogy of Fallots." His diagnosis of Down syndrome was a complete shock to us and I struggled with "why" for most of the first year of Conor’s life.

We assumed that life would be difficult for Conor and for ourselves. We also assumed that one of us might have to give up our career.

Conor surprises us every day of the week. His speech is excellent. He plays Tag Rugby, Netball, Basketball with the Special Olympics; does horse-riding and is learning how to swim.

I left my job at the bank to set up my own business so I would have flexibility around Conor’s appointments and this allowed me to keep my career going. 12 years later and my business is thriving, without having Conor I may never have done this!

The Challenges
Conor’s medical challenges overshadowed everything else for the first five years and eating and nutrition was also a big challenge until recently. Life will always be challenging for Conor. He has residual leakage of the pulmonary valve in his heart following a repair and therefore doesn’t have the same stamina as other children. Conor wants to be the same as his cousins but his life is different, it’s unavoidable.

The Medical
At the end of his first year, Conor underwent the first of many surgeries. This was a ‘Tetralogy of Fallots’ repair which was an eight-hour open heart surgery and Conor did well to survive. He fought the brave fight and continues to do so today.

In the last fourteen years, there have been numerous trips to hospital; Grommets, T-Tubes, Eye Surgery, Plastic Surgery; end once for pneumonia. Plus, one scary trip after he was knocked out on the football field that turned out to be a "straight-forward" knock-out.

Conor has a mild to moderate hearing loss and recently needed hearing aids and is awaiting customised orthotics for problems with his feet.

The Highlights
Conor received a bravery award from Our Lady’s Children’s Hospital, Crumlin after his first surgery. He has been awarded three All-Ireland Medals for Variety Show Performances with Singa Academy, Newbridge. He has also achieved first class honors in Grade 2 Speech and Drama Exam and received the Leinster School of Music and Drama Excellence Award in 2014. An outstanding achievement!

Family Life
Conor is Jim’s biggest rugby fan and loves to attend all of the matches with us. He also supports Mon United and Leinster Rugby in his spare time so our family life revolves around sporting interests.

Amanda and Keelin
Proud and DAD to Conor 14.
Down syndrome usually occurs by chance at conception. It is identified by the presence of an additional chromosome in a baby’s cells.

There are three types of Down syndrome, Trisomy 21 (nondisjunction), Translocation and Mosaicism. 95% of occurrences result in Trisomy 21, 3-5% in Translocation and 1-2% in Mosaicism.

Down syndrome occurs in all countries of the world and is not discriminative of race, religion or socioeconomic status.

Babies with Down syndrome are born to mothers of all ages. Older mothers have a higher individual chance of having a baby with Down syndrome, although more are born to younger mothers, reflecting the higher birth rate in this group.

A person with Down syndrome will always look more like his or her close family than anyone else with the condition. There are certain physical characteristics that can occur and people with Down syndrome can have all, or none of these.

Children and adults with Down syndrome are all unique individuals with their own likes, their own strengths, their own characters and experience a full range of emotions.

Children with Down syndrome are successfully educated in mainstream and/or specialist early years settings, primary schools and secondary schools. Some young people gain their Leaving Certificate, and some further their education and attain vocational qualifications.

More and more adults with the condition are in paid and/or voluntary employment, maintain good friendships and loving relationships and are living semi- or fully-independent lives.

Many people with Down syndrome are achieving typical life goals and are living into their 60’s and beyond.

... dispelling the myths

Down syndrome is one of the most commonly occurring genetic conditions. It is currently estimated there are approximately 7,000 people in Ireland who have Down syndrome.

Society’s knowledge and understanding of the condition has increased over time. However, the general perception of life with the condition continues to be shrouded in myth.

Let’s dispel some of the most common myths with some facts.
At 21, I found out that I was expecting my first baby. Aleksandra was born 5 weeks early weighing approximately 5lbs. She was put into an incubator to help her maintain her body temperature and although I had planned to breastfeed, she had very weak reflexes and needed to be tube fed. After three days, the doctor told us that Aleksandra has Down syndrome and three days after that, she was transferred to Our Lady’s Children’s hospital, Crumlin where it was explained that she would need heart surgery.

We loved her from the minute we found out we were expecting and couldn’t believe that this was happening to us. Every time we looked at our baby we thought she was perfect.

Aleksandra is now 8 years old and is attending mainstream school. When I look at Aleksandra I don’t see Down syndrome, I see a healthy girl who has beautiful eyes, a wonderful smile and a very good sense of humour.

The Challenges
We are originally from Lithuania and we communicate in Russian at home, so Aleksandra has been learning two languages from birth. She has difficulties with her speech and attends regular speech and language therapy, occupational therapy and physiotherapy where she is progressing very well.

The Medical
At 7 months old Aleksandra had gained the weight necessary for her heart operation, an ASD repair. This was the hardest and scarest experience of our lives but she was draining and the surgery was successful.

The Nighttime
One of the happiest times for us was when Aleksandra started walking at 26 months. When she was 6, we were flying to see our grandparents in Lithuania and Aleksandra was sitting in the plane, she said ‘Mummy, we are going to fly’ in Russian, I nearly started to cry with joy because she hadn’t previously spoken in full sentences.

Family Life
We spend time as a family outdoors, traveling and going to activity centres. Aleksandra has a little brother Danili who is 4 and she loves him a lot, she helps me care for him. I always call her a little Mummy.

Finale and Aleksandra
Parents of Aleksandra 8 and Danili 4.

"... I see a healthy girl who has beautiful eyes, a wonderful smile and a very good sense of humour."
John

My name is John
I am 40 years old and live in Moyvane in Kerry

Education
I want to learn painting but did not like when the teachers shouted. I love going to college where I am doing the Latch-On (Literacy and Technology Hands-On) course and the NOTE (My Opinion My Voice) course.

Interests
When I was a child I loved playing in Moyvane playground and I liked tractors, motorcycles and lorries. Now, I love computers and I like writing and watching the Late Late show with Mom. I like to help brush the floor and putting the clothes in the washing machine.

Employment
I work in a bookshop called 321 and also at Spar. At 321 I put books in bags and talk to customers and at Spar I put bottles in the fridge. I work Tuesdays and Thursdays and I’m paid for my work. I’d like to work with computers and PowerPoint.

Family
I live at home with my Mum and Dad. I have four brothers, three sisters and one sister-in-law. I love having my four nieces and five nephews at home, my family is the most important thing in the world to me.

*Latch-On and NOTE form part of Down Syndrome Ireland’s Ability Programme, which aims to provide people with Down syndrome access to meaningful employment opportunities.*
Mary Claire

My name is Mary Claire
I'm 25 years old and live in Currow, Killarney Co. Kerry

“The most important thing in the world to me is meeting up with my friends.”

Education
I went to school at St Oliver's in Killarney. My favourite things were playing games, art, music, cookery and drama. I didn’t like teachers giving out homework and hated getting up early.

I'm currently training as a hairdressing assistant* every Wednesday for 11 weeks.

Interests
When I was young I loved playing with my cousins in Glenbeigh. I'd watch Barney and Friends on TV and Mr. Bean. Now I like hairdressing, swimming, reading and dancing. I like doing art, going to the gym, watching DVDs, dancing, swimming, reading and meeting up with my friends.
The most important thing in the world to me is meeting up with my friends.

I do Latch-On* (Literacy and Technology Hands-On) each Thursday and on Fridays I do HONE* (My Opinion My Vote) and I love it, this is my second year.

Employment
I work at Nana Bees cleaning tables, tidying books, washing dishes and talking to customers. I'm paid for my work and I love my job. I work here Mondays and Tuesdays.

In the summer I work in Deenagh Lodge cleaning, brushing the floor and cleaning off the tables.

Family
I live with Mom and Dad. My brother lives in Dublin. He is a teacher. I have lots of cousins, I love to go to the beach with them. I love being with Mom and Dad - we love to go to the beach in the summer. My brother comes to see me at least once a month and in the summer I go to Dublin to see him and we go to the cinema.

*Beauty in all its Forms – which trains people to be hairdressing assistants, Latch-On and HONE, all form part of Down Syndrome Ireland’s Ability Programmes, which aims to provide people with Down syndrome access to meaningful employment opportunities.
Louis

The 22 week scan showed soft markers for Down syndrome. I left the room in tears. I felt tormented. I chose not have an amniocentesis, as I knew people around me would try and influence me if it indicated Down syndrome. I prayed I would be able to cope with whatever came my way. It was a long 16 months and I cried daily. It took several hours after the delivery for medical staff to see what I saw. Louis had Down syndrome. I felt scared and sad for Louis and terrified that life as I knew it was over.

Louis is extremely happy in 2nd class at mainstream school and he’s a super reader. Horrid Henry books are his favourite. He attends Bewers every week and has had 2 nights away with them on camp. He was so proud of himself afterwards. I know that I made the right decision over 9 years ago. For me, it was better not to know.

The Challenges
The hospital and therapy appointments in Louis’ early years were exhausting. Louis had a speech delay but with speech and language therapy he now has good speech. When Louis started school he wasn’t entitled to any learning support as he had an IQ in the borderline range. He was later diagnosed with dyslexia and now has the support he needs.

The Medical
Louis was in hospital frequently in the earlier years with recurrent pneumonia from aspiration, febrile convulsion and kidney infection. He had surgery on his baby button, and had his adenoids and tonsils removed. He’s due to have surgery to repair a perforated eardrum. Louis attends an ophthalmologist for severe long-sightedness and a squint and wears a hearing aid and therapies to help with his vision.

The Highlights
After every appointment we’d go somewhere special... the Zoo, Imaginately, playgrounds, MiMo’s for pizza, icecreams... all thanks to my Mum who helped with his siblings. Harry and Charlie associated their little brother with fun and adventure. In return they bullied and dragged him along... These were the best physiotherapists he could have!

Family Fun
Today I rush in the front door from work greeted by squeals of delight from Louis. He jostles with his brothers and dog Riley to give me my welcome home hug. His joy and happiness is intoxicating.

Sandra and Ronan
Sorcha

Our beautiful baby girl was safely delivered by emergency section in September 2011. I instantly knew that she had Down syndrome. The paediatrician confirmed it and it felt like the bottom fell out of our world. I worried about how this would affect her brother and sister. I worried about her future. I knew nothing about Down syndrome, I was given the most helpful advice by a nurse to just treat her as the baby she is. Be her mum because that’s who she needs right now. The same as any baby. When we took her home everyone fell in love with her, most of her brother and sister and over time; I stopped worrying about what lay ahead.

Sorcha has changed all our lives for the better; she is a bright and bubbly little girl with a lust for life that brightens everyone’s day. She does not get angry in her way, she does gymnastics, athletics, ballet, and plays football.

The Challenges
At the start I found it difficult with all the appointments and missed a few along the way! There are significantly less appointments now so its much easier to manage. Sorcha has sensory processing issues and required a lot of intervention to help her manage them. She has childhood tremors and sleep apnea, which can result in hypersomnia during the day. She has a tendency to bite and requires full supervision when outside.

The Medical
Sorcha was born with a heart defect. Complete AHSO which was repaired when she was 11 weeks old and in heart failure. A second surgery was needed which meant her first Christmas was spent on life support, which has been the hardest part of our journey. Sorcha fought hard to survive and to this day she is the strongest person I know. Sorcha has bilateral hearing loss and wears hearing aids, which help her tremendously. She has swallow issues and has a food replacement drink and thickened fluids to accommodate.

The Highlights
Sorcha started walking when she was 2 and a half and hasn’t stopped! We were thrilled when she signed her first word, and she now has a huge vocabulary of signs and some words. She joined up some lessons as her sister is a budding ballerina and gymnast. Sorcha started mainstream primary school this year and is very popular with the other kids. She communicates using LamiH sign language and the whole school have been learning to sign.

Family Life
We travel to France every year and love spending time together in the pool or out and about. Sorcha loves playing football with her Daddy and we all love getting out in the fresh air to the park or the beach to run and burn energy!

Colette & Shane
Parents to Tara 13, Eoin 10 and Sorcha 6.
Sadhbh

Initially, our feelings were of shock and disbelief, followed by grief for the loss of the life we were expecting. After a few months, feeding and nappy changes, it was easier to see similarities between Sadhbh and her siblings. We knew nothing about Down syndrome and concentrated on Sadhbh’s abilities rather than her disability. We had to learn that, while Sadhbh shared traits and features with her peers with Down syndrome, she is, most definitely, a unique individual.

Sadhbh grew up the same as her siblings. She laughed, cried, pouted and engaged with society. She thrived on consistency and routine, as did her siblings. She took a while to master some skills, but the important thing was that they were learnt.

“The Challenges”

Age-appropriate behaviour was a challenge for Sadhbh, especially in her younger years. Communicating with strangers can be challenging, but Sadhbh perseveres. Sadhbh wants to be like her peers, to be allowed to do as they do and although this is challenging because Sadhbh’s needs differ, she holds on to it.

“The Medical”

Sadhbh has a successful AVSD repair at two and a half years old. She is on a preventative inhaler over the winter months. Her medical status doesn’t impact on her enjoyment of, or participation in, everyday life.

“The Highlights”

Highlights in Sadhbh’s life are many and varied. They range from standing, walking and talking in her early years to participating in the Special Olympics Ireland Games 2018. She has led a local St. Patrick’s Day Parade, she has performed solo with a samba band, she has celebrated the BEST 15th birthday and party … the list goes on.

“Family Life”

Sadhbh has four siblings. She learns more from all her siblings than she could ever learn formally, things like sharing, turn-taking, fighting her corners, apologising. Two of her sisters are close to her in age and she strives to do as they do, especially socially and regarding independence.

Having Sadhbh in our family has made us all more aware of, and more comfortable with, others with disabilities. We are all more accepting of difference and individuality.

Ellen and Kevin

Parents of Sorcha 21, Sadhbh 19, Meadbh 18, Diamhad 15 and Mae 12.

“... while Sadhbh shared traits and features with her peers with Down syndrome, she is, most definitely, a unique individual.”
Education
I finished school last June. In September I started a 3-year training course at College with Cope Foundation.
My course is Monday to Friday until 4pm. I walk there and back with my friend. College is ok. Some of the teachers are strict. My favourite subject is Computer. I go out to Music-Mash-Up (mixed-up music) one afternoon a week and I really enjoy that.
The best thing in College is lunchtime with my friends, the worst is being corrected by teachers.

Interests
My life is ok. It’s not amazing yet because I really want to be on stage and sing, with the amazing support of my family. I have a very busy life. I meet my friends at Special Olympics gymnastics, swimming and table tennis.
I will compete in the Ireland Games in gymnastics in June 2018. I go to dance classes and music classes. I play the bodran. Music-Mash-Up helps me with drums, keyboard and the ukulele.
I like take-aways with my friends. X-Factor on TV and on tour, I like listening to music and singing along, meeting my friends, going to concerts, staying up late and wearing comfy clothes.

Employment
I don’t currently have a job. I really want to work. I’d like to be a lifeguard on Bondi Beach, or a singer.

Family
I have three sisters and one brother. I am the second eldest. I get on best with my sister’s boyfriend. We go spinning and singing in the car and talk about X-Factor. My youngest sister, asks me to turn down my music when she’s trying to get to sleep.

Sadhbh
My name is Sadhbh. I am 15 years old and live in Cork City.
Ruairi

My name is Ruairi
“Ruairi” means red-haired king – I have red hair!
I am 24 years old and from Celbridge near Dublin

Education
From 3 to 5 I went to the special pre-school at St. Raphael’s. I loved it. I attended an outside Montessori pre-school then for a year. From 6 to 18 I attended the Special School in St. Raphael’s. I learned swimming, pony-riding, dancing, reading, writing, games, gymastics, pottery and painting. I didn’t love it when I had to stop swimming or games when they were over. When I was 8 I won a prize in pony-riding for the Special Olympics Leinster trials. Jean Butler of Riverdance presented the prizes.

Interests
I enjoy my activities at the training centre, choir, drama, football, film production, swimming, bowling, basketball, theatre and cinema. I have been dressed in Mama Mia and other live musicals. I like to help Mam and Dad. I split the logs for the fire.
I especially love going to the Arch Club every Wednesday. I dance non-stop from 7 till 9pm. I enjoy swim training for Special Olympic. I won a bronze medal for golf skills at Ireland’s Special Olympics.

Employment
I’ve job shadowed in Tesco. I’ve done some work experience, which I was paid for. I am learning a lot of skills.

Family
Mam, Hannnuala; Dad, Michiel; my brothers Mum and Cannal. Mamó, my granitic, lived with us during my home. Mamó played boil with me, and watched hurling and Gaelic football, especially the All-Ireland finals.
We loved to go to Mamó’s house in Donegal, near the sea for the holidays. I love the sea. Mam and Dad are the most important people in my world. I often tell Mammy and Daddo “Ruairi happy!”
Jordan

We found out immediately after our son, Josh, was born. While my husband was with Josh a doctor said ‘he looks like a child who has a syndrome’. Our euphoria was very short lived. We were utterly devastated, especially to find out in such a cold way.
We cried, endlessly. We didn’t feel like celebrating, we felt sadness (for ourselves, our son and our family), a huge sense of loss and we were already putting limitations on him. Every single thing we had imagined for our family life would now be very different. It felt like a huge burden.

I had assumed that people with Down syndrome developed the same as everybody else but I never actually had to think about it. The reality is quite different. The developmental delays can be difficult to accept. At 31 months Josh is now walking independently. He has only basic words (mama, dada, ba-ba) and is learning Láth, his constant sign is food. He is very vocal and loves throwing everything on the floor.

The Challenges
It is hard not to get frustrated that milestones aren’t achieved as soon as you would like them to be. We had to just tell ourselves things will happen, just let them. Forcing won’t change it.

The Medical
Josh was diagnosed with Hirschsprung’s three days after he was born. He had an operation that July and it was successful. We had a setback a couple of weeks after the operation and felt utter desperation at the situation but there was light at the end of our tunnel. Josh also had a feeding tube in initially and was taking a special high calorie milk. This continued for a few months and was very restrictive, time consuming and heart breaking having to change the tubes and trying to keep his little cheeks from getting sore. His health is now quite good, he has no hearing or sight difficulties.

The Highlights
Bringing Josh home from his two hospital stays initially and after the surgery. Achieving milestones are celebrated. I did a little happy dance when his first tooth came through.

Family Life
Life is busy with appointments and trying to do our best for both of our children. Josh loves play school, he attends 2 different places and really enjoys them both.

Olivia and Keith
Parents of Amelia 4 and Josh 3.
I was 17 weeks pregnant when told our baby has Down syndrome. The next 24 hours I felt alone, shocked, sad and scared. The one thing I knew for sure was that this was my very much wanted baby and I was keeping him.

We assumed that our lives would be turned upside down, that nothing would ever feel okay. Our family is full of doctors, all giving advice from a medical perspective, but this was our son, not a medical case.

Enzo burst into our lives 3 weeks early and has been surprising us since with his beautiful, cheeky and determined nature. Our family is complete, our daughters adore their little brother and we couldn’t be happier.

The Challenges
Telling family and friends was not easy. Other people’s reactions of shock and sadness and questions like “Are you going to keep your baby?” The future definitely sorted out who our true friends were.

The Medical
After an unplanned home birth Enzo had a twelve day hospital stay for severe jaundice and to establish feeding. Enzo had two holes in his heart and 1 PDA, all of which closed by seven months. He came home with a feeding tube but by a month old he was fully breast feeding. Enzo wears glasses to treat a squint in both eyes.

The Highlights
Watching Enzo grow and develop, seeing the bond grow between our three children. Each time one of our children achieves one of their goals it is something we celebrate as a family. Eve getting to grips with reading, Eliza moving up in her ballet class and Enzo being able to sit up in his high chair at meal times to eat with us. We all met when Enzo gives us one of his gorgeous smiles.

Family Life
Enzo completes our family, we feel that he chose us and that we are so lucky to have all three of our amazing children. Family life will always bring its challenges but with good support, correct information and the support of family, friends and the medical professionals we will all be just fine.

Shanaz
Mum of Eve 6, Eliza 3 and Enzo 8 months
Zach

It was love at first sight for our son, Zach but with this love came the strangest mix of emotions – love, incredible sadness, disbelief, a sense of failure. We were totally and utterly devastated. We wanted to be airlifted to somewhere where we didn’t have to face people.

We assumed nothing - decided to read as little as possible into what he wouldn’t achieve and just take each day as it came. The reality was at first painful - we didn’t expect that the services available to our son would be so limited, especially after he insisted on early intervention. I feel I missed his early years feeling that it was somehow less valuable, less relevant than the other children in the family. I thought other people tilted us as parents and this feeling of loss cut deep. I wasted these early years and wish I had known that everything would be more than OK.

The Challenges

Zach has difficulty getting dressed as his fine motor skills are not great - dressing, tying shoe laces, opening doors, brushing his teeth, holding a pencil all need help and supervision. He has to be reminded to flush the toilet and to wash his hands every time after his younger brother is in the bathroom. He is very macho and lives off everyone but will do what he is told, especially when it’s his father doing the asking. Our challenges are mainly with school, Zach is not yet literate and we’re trying to get the school to take on a literacy programme to help.

The Medical

Zach is now 11. He has a small ASD which was last checked when he was 4 and he is not on any medication. Last September Zach had his tonsils out which he recovered from with remarkable speed. He has loose joints and requires shoes for his knees. He is healthy at average height within the range for those with Down syndrome. His difficulties with his teeth as some of his baby teeth have not come down and he will have to get a brace in the next year.

The Ingredients

Zach is the LOVE of our lives, he is MAGNIFICENT. The love and joy that radiates from our son is remarkable - true - he is a manipulator, tortured, comical, drama queen, lazy as sin but also he is so funny, so full of crap, very much in touch with his feelings and he makes my heart sing (most of the time).

Family Life

Zach is happiest when he is in the company of others. He is lazy by nature, but loves karate, swimming (he is in his local Special Olympics swimming team), bowling with his father (for 10 minutes, 10 at a time, but he still loves it) and making up plays with his grandparents and listening and singing to CD’s. He loves sleepovers, going to the cinema and family holidays just like his little brother. We enjoy fine dining, travelling and Zach engages brilliantly with young and old.

Anahm and Alan

Parents of Zach 11 and Alex 10.
This booklet is made available to you by the generous donation of Ian and Heather Fleming and the collaborative efforts of Down Syndrome Ireland and its members.

Anna Fleming with her Mum Grace

My sister Anna Fleming was born in 1956, she lived past her 50th birthday and engaged with everyone she met. She was outgoing and interested in people – especially couples, always asking about the partner and/or children. She had a phenomenal memory for names. Anna was competitive, sometimes abrasive, and could be difficult at times. She loved music (especially that of Daniel O’Donnell) and dancing – until old age caught up and she would dance no more. Anna was kind hearted, caring and demanding of justice. Above all she was independent minded, which had its own consequences. She cherished her possessions: her bag and its treasures, her necklaces, the large number of bracelets she adorned her wrists with and her three small rings on her fingers. Anna was competitive and a great one for pranks. She loved the staff in Cape who were so good to her and she loved when her family called in and on whom she had an affection. Anna’s funeral was a time of celebration of her life and the family learned of the many people she affected positively during her lifetime. We knew life with a family member who has Down syndrome is challenging but be assured the rewards far outweigh the inconveniences.

Thank you for taking the time to look at this book, I hope it has been helpful to you.

To the individuals and families who have contributed to this booklet, thank you. Sharing your very personal experiences and photographs is incredibly gracious. Your contribution provides an important and realistic perspective of life with Down syndrome or life with a child or adult who has Down syndrome that would otherwise not be available.

Down Syndrome Ireland is a national organisation which has 25 branches offering support and services, information and a listening ear for parents and families across Ireland. Most of all, we are a community of people who share the same journey.

For support, information and advice on all aspects of living with Down syndrome, you can speak to Down Syndrome Ireland on 01 426 6500 or visit downsyndrome.ie.

[1] 01 426 6500
[2] info@dowsyndrome.ie
Lose the Label is a grass roots initiative dedicated to educating and updating social perceptions. Helping society adopt a new language with an equality in terms of reference for children and adults with Down syndrome.

Photographic campaign
Our photographic campaign gently challenges outdated stereotypes and provokes thought about society’s perceived knowledge and the language used for individuals with Down syndrome. The campaign is delivered via social media and through highly impactful exhibitions.

Training:
Outdated knowledge is what forms negative perceptions from clinical professionals, healthcare workers and communities. We update this knowledge through a thoughtful, personal approach by those that live the reality today.

We discuss the impact language and outdated knowledge has on individuals, their families and communities and offer guidance on how small changes can positively impact the life opportunities of those with the condition and contribute to a more positive experience for all.

“...more than medical”
This booklet is a tool for professionals and a resource for parents from the very beginning of discussing prenatal choices, through to a postnatal diagnosis of Down syndrome for their baby.

Facebook: facebook.com/LoseTheLabel
Twitter: twitter.com/Lose_the_Label
Website: losethelabel.co.uk

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