Parent and Toddler Group

Central Remedial Clinic

Stories written by parents

October 2010

PARENT & TODDLER

GROUP

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Introduction

The Social Work Department of the Central Remedial Clinic established the Parent & Toddler Group in 2000. A few parents requested a place where their children could play together and where they could meet other parents in a similar situation. Local Parent & Toddler Groups did not always understand what it was like to have a child with disability and several CRC parents did not feel comfortable attending them.

After an initial 6 sessions, 6 parents and their children continued to meet weekly. They invited others with children younger than 3 years to join them and share their experiences. The parents decided the aims of the group:

- to foster mutual support
- to reduce isolation
- to give parents information on services and entitlements

Facilitated by a CRC social worker who organises speakers, outings and a Christmas party, the group is now in its 10th year. Although it has grown and developed over the years, its original format, designed by the parents, remains intact.

The stories in this booklet were written by some of the parents who left the group as their children grew and progressed. These parents wanted to write their stories in the hope that they might assist others facing the same struggles. We are indebted to them. Every story shows their huge love

and dedication to their children. We are also grateful to all of the parents who have shared their experiences and supported each other over the years.

In putting these stories together we are grateful to Jane Mitchell who has kindly helped us.

Geraldine Prunty
Principal Social Worker
October 2010

Shea's Story

'Nothing could have prepared me for the results'

My son was diagnosed with Cerebral Palsy in August 2006. This is my story: a journey filled with so many emotions.

When Shea was born, I felt the luckiest woman on earth. He weighted in at 8lbs 1oz, with thick curly hair and big blue eyes. I had the perfect baby. To begin with, he reached his milestones. He rolled over at four months and was drinking out of a beaker by six months. I didn't think for a second anything could be wrong.

When Shea reached his first birthday, I noticed he wasn't even attempting to crawl. And I noticed that he would sometimes sit to the left side of the buggy. My instinct told me something wasn't right so my health nurse referred me to Temple Street Hospital where Shea had numerous blood tests and examinations. He was called back for an MRI scan.

Nothing could have prepared me for the results when the Consultant told me my son had Cerebral Palsy (Diplegia). I was numb, then the tears came. I couldn't even ask what the

future meant. I couldn't speak through crying. All I knew was that my beautiful baby boy had a disability for life.

A few months later, I walked through the doors of the Central Remedial Clinic. I was so nervous but tried to be brave for my son's sake. During those first few weeks, I learnt all about Cerebral Palsy, and how it affected Shea. The Physiotherapist told me Shea had a mild form that affected both his legs but that he would walk and run. I was so happy to hear that news that I cried then too.

I was attending Physiotherapy for a while when I heard about the Parent & Toddler Group held in the Clinic. I went along not knowing what to expect. I mainly went for Shea. At the time, he was such a clingy little boy who wouldn't leave my side. After a few weeks in the group, I felt so much more positive. It was a great help talking to other parents, each with different experiences, but all of us shared the same feelings.

During my time at the group, I've met some amazing people and I hope they'll be my life-long friends. We have lunch together at the Central Remedial Clinic after the group. We meet up for outings in the summer and get together on special occasions, such as the children's birthdays. The group has given me so much advice; I could not have got through these times without them.

As for Shea, he's a different boy now than he was when he first started in the Central Remedial Clinic. He's walking now. He has Physiotherapy, Speech and Language Therapy and

Occupational Therapy. He also sees the Consultant every four months. He has his bad days when his legs get tight and he suffers with weak shoulders and weak hips due to his condition, but Shea is getting stronger by the month. He has gained so much confidence due to attending the Central Remedial Clinic and I am truly grateful to all his therapists, the Social Workers and my very good friends at the group.

Before we started in the Clinic, I felt like a black cloud was hanging over me. While I still get my bad days, I feel much more positive about Shea's future, knowing he will get the help and support through his life, if and when he needs it.

Matthew's Story

'We don't know what the future will bring'

My name is Avril and I have a little boy, Matthew. He was born in 2004 and needed medical attention at birth so he was kept in the special care ward for a week. He was then transferred to Crumlin Hospital for investigations, but all the tests came back clear, so we were sent home.

I sat with Matthew for hours trying to get him to suck his bottle. It was so hard, but he was a hungry little baby and eventually started putting on weight so I was delighted.

When Matthew was 3 months old, I became concerned because he didn't seem to be able to hold his head up himself and he always slept on the same side. We were referred to the hospital Physiotherapist, who gave us exercises to do with his neck. She also noticed his feet were a little tight.

I knew at this stage that there was something not right. The hospital organised home Physiotherapy every week and even at this early stage I heard Cerebral Palsy mentioned. I think I just tried to block it out.

At 5 months, Matthew started having seizures. I didn't know what they were at first because they weren't like typical epileptic seizures that I'd heard about. It just looked like Matthew was trying to sit up, but I knew by his eyes that it was something more serious.

An MRI scan came back normal, but I didn't know whether to laugh or cry. It was great that it was normal but I still knew there was something wrong. Matthew wasn't able to do anything a child of his age could. I felt helpless.

The neurologist set up an EEG to test for epilepsy and Matthew was diagnosed with infantile spasms. He was started on medication which stopped them instantly. It was a great relief because they had been making him so tired, but physically, Matthew was making no improvements. He made no eye contact; smiles were few and far between. It hurt us to see other babies his age laughing with their parents.

Eventually, he was diagnosed with Global Developmental Delay, but so many disabilities fall under this heading that I nearly drove myself crazy looking at different websites.

When Matthew was 9 months old, he was referred to the Central Remedial Clinic. I was a little shocked at this but I would have done anything to get him help. I decided this could be a very positive move for him. The Physiotherapist there focussed on what Matthew could do and what we could work on. It was great to meet someone so positive and I looked forward to the sessions. Occupational Therapy and Speech Therapy followed. It felt good to be actively doing

something to help Matthew.

The Social Worker invited me to the Parent & Toddler Group and it was the best thing I ever did. The relief of meeting other parents and the support I got was invaluable! Matthew was just another child in the group and not defined by his disabilities.

At 14 months, Matthew's seizures became more severe. He was admitted to Crumlin Hospital and for the next week, was having up to 24 seizures a day. They gave him steroids by injection 3 times a week. I had to learn how to inject him, which was awful and I was very upset. It was just so hard seeing my little boy this way, but within a few days, he was much improved and we could take him home. I continued injecting Matthew for 6 months. His seizures stayed under control and he started taking notice of things, smiling and laughing. His work in therapy improved also.

Matthew had his eyes and ears tested. While his hearing is normal, I knew he had sight difficulties because he didn't make eye contact or look at faces. After meeting with the eye doctor, the National Council for the Blind got in contact. I was confused and heartbroken. Was my baby really blind? Matthew really loved his food so I used that to get him to look at things, like the spoon and his cup. We were put in touch with St Joseph's School for the Blind and it was only then that I started to understand Matthew's visual impairment. He had some great therapy sessions with them and his 'looking' greatly improved. It's still getting better and better.

By the age of two and a half, it had become clear that Matthew's intellectual needs were as great as his physical disabilities, so a decision was made for Matthew to transfer to St. Michael's House services. I was very sorry to be leaving the Central Remedial Clinic but I was fully convinced it was the best thing for Matthew. They organised home Physiotherapy and Occupational Therapy, and a Speech programme, as well as a home teacher. He also attended St. Joseph's School for the Blind once a week for visual stimulation work. The improvement in Matthew, socially, was immediately noticeable. He was becoming more adaptable to new situations and people. It was great!

When he was three, Matthew started pre-school, attending St. Michael's House twice a week and St. Joseph's twice a week. Neither could offer him a full-time place at the time, but this worked in Matthew's favour. Once he got used to the routine, he loved going on the bus to both schools. To begin with, I sat at home not knowing what to do with myself, but once I started getting good reports in his school notebook, I relaxed and started to enjoy my time. He was receiving all his therapies at school too.

Matthew now attends St. Michael's House special needs school. He loves it, and hates when he has to take a day off. He does music, painting, swimming—all the things children of his age love. He is non-verbal, but communicates very well in his own way, and is generally very happy. He can be as funny or as naughty as any other child.

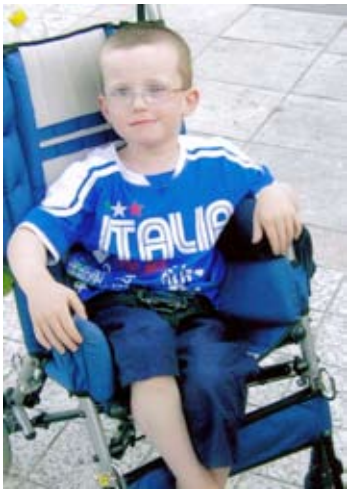
We’re still figuring out the reason for Matthew's disabilities. He’s recently been diagnosed with a rare disorder called Adenylosuccinate Lyase Disorder or ADSL. Not a lot is known about this as there are only about 60 diagnosed cases in the world. It was a bitter-sweet diagnosis for us, as it was great to have a name on it and great to know we’re doing exactly what we can for Matthew, but it's hard that there's no treatment and we don't know what the future will bring.

We could have more tests done, but how much do we really want to know? We'd love to know everything about Matthew and why he's so special but how much should we put him through to try to satisfy our curiosity? For the moment, we're going to enjoy him and every personal milestone he reaches, no matter how small.

Matthew is a special gift and gives us endless pleasure…we've enjoyed every moment with him so far and will continue to do so in the future.

Luke F's Story

'The not knowing was the hardest'



Luke was born in 2004 and weighed 10lbs 11ozs. He seemed to be a healthy little boy until he was about 4 months old, when I noticed he wasn't doing the normal things for his age. He appeared to be floppy. He couldn't hold his head up. He didn't move his arms and legs as much as he should have. He mainly ate and slept, and had a recurring cough. My doctor referred us to Temple Street.

Having seen Luke, the specialist in Temple Street said there was something wrong with him, but he didn't know exactly what, so he arranged for Luke to be an in-patient for a week. It was then that reality hit me. I broke down and cried. I was scared and didn't know what lay ahead. I had two other children at home. How was I going to tell them there was something wrong with their baby brother?

When I tried to tell my husband, I kept breaking down. I worried about the future, but he was calmer. He said that whatever happens, happens. We would just have to learn to cope and get on as a family.

When Luke was in hospital, numerous tests were carried out. When the doctors learned that he had been throwing up since starting on solid foods, they sent him for a video x-ray and discovered that liquids were not going straight into his stomach. Some was going into his lungs, which could cause pneumonia. His liquids had to be thickened to a paste, which meant he had to be spoon fed all his feeds. The nurses were a great help with the feeding, however this was another worry for me. How would I manage when we got home?

Luke was seen by a Metabolic Specialist and was readmitted a month later for a muscle and skin biopsy. I was terribly worried about the biopsy, mainly because of the anaesthetic and also because metabolic conditions can come with heart problems. Eventually Luke was diagnosed with Mitochondria Disorder Complex 3 & 4. This means that the energy cells inside his muscles are affected, which gives him very low energy. To help with this, he was put a high fat diet and a combination of vitamins. He also takes a food supplement called co-enzyme Q10, which helps boosts his energy levels.

The specialist explained that it was a rare condition and that tablets prescribed would help him. I kept wondering if Luke would have a normal life, would he ever crawl, walk, or talk. The not knowing was the hardest. As this condition is genetic and carried by the parents, I was terrified that my other children could be affected in some way, but the doctors said they're active children and didn't have any of the symptoms.

I was told that if I ever got pregnant again, there was one chance in four that the baby would have the same condition.

I didn't plan on having any more children so there was nothing to worry about, but then found out a few months later I was pregnant again. I was horrified, because I knew the risks. During Luke's check-up, I told the doctor I was pregnant and he suggested a blood test to determine if I carried the gene. The results came back and I was not a carrier. Good news at last! I went on to have a beautiful healthy baby girl.

At one year four months, Luke was still unable to roll or sit or support himself unaided. We attended the Central Remedial Clinic for Physiotherapy, Occupational Therapy and Speech Therapy. I heard about the Parent & Toddler Group; Luke's Social Worker invited us to come along as it would give Luke the chance to play with other children, and me a chance to chat with other parents. I gave it a go and haven't looked back since. It has helped me in so many ways.

It's a great help to be able to talk to other people in a similar situation. The group is a great source of encouragement. They are there to support you when times are good or bad. It is great to see how all the children progress and how the parents learn to cope better. Some people find it harder than others to cope but no-one is ever judged. They are always encouraged by the team and the other mothers.

Sometimes we have talks from Physiotherapists, the Seating Department and other departments. The Physiotherapists explain how we should be carrying our children and the Seating Department gives us advice on car seats, buggies etc.

The group also organises outings twice a year, usually to a play centre and to Newbridge House and Park. They also arrange a Christmas lunch. Santa arrives and gives presents to everyone. To end off, there's a sing song.

One of the most important things you learn from the group is about the entitlements available to you. When I first attended I didn't know about all the entitlements available for disabled children. This information is invaluable as neither the hospitals nor the authorities inform you of these.

The CRC also provide respite carers for a number of hours each week. They are a great help as it gives you a chance to have some time to yourself or to spend time with your other children.

Luke has two sisters and a brother who are perfectly healthy. His little sister has brought him on in so many ways. He never attempted to crawl until she did. Now as well as flying around the house after her, he has also followed her up the stairs. He's able to climb on and off the sofa unaided.

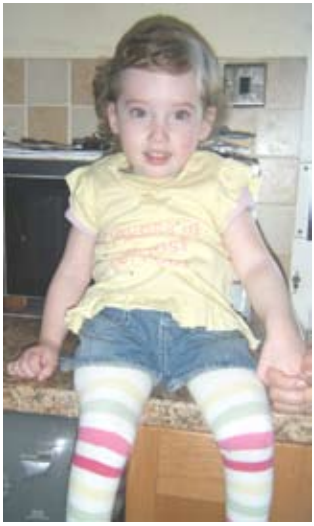
Luke has come on in leaps and bounds. He is now able to sit up unaided and communicate a lot better. He loves music and the songs they learn at the group. Whilst he is unable to talk at the moment, we are hopeful that he will one day.

He will be attending main-stream pre-school in September, with the help of a teacher's assistant. We are hopeful that a routine will bring him on even more. All in all, the future looks positive.

I would like to say a special thanks to the Social Work team for starting up the group, which has helped us as a family. I hope it continues to grow strong to help other families in similar situations.

Sophie's Story

'These last few years have been a leap into the unknown'



Hi, my name is Deborah and this is a story about my daughter Sophie. After two healthy boys, I hoped to be blessed with another healthy baby (secretly hoping for a girl, so I could finally buy everything pink).

The pregnancy went smoothly with no problems, but that all changed, as did our life, during a routine 39 week scan. The doctor told us our baby had Hydrocephalus, but reassured us there was no Spina Bifida. It was decided, for precautionary reasons, that I would have a Caesarean section the following morning, 14th April 2007.

Upon delivery, our delight at the sight of our beautiful daughter, Sophie, was quickly replaced with worry when she was taken away to ICU. We assumed it was the Hydrocephalus, although Sophie appeared perfectly normal to us, but after a short time the doctors came back to tell us that although Sophie's Hydrocephalus was mild and had not caused any problems, she had Spina Bifida. She was

transferred almost immediately to Temple Street, where she underwent surgery on her back at just 1 day old.

A week later, Sophie had a shunt installed to control her Hydrocephalus. Unfortunately, this blocked after 2 weeks and there was more surgery. Those early weeks were the hardest. I was recovering from my Caesarean section, dealing with the shock, going in and out of Temple Street with my infant daughter and looking after our two little boys. Everyone in the hospital was fantastic support to us during this very difficult period. Sophie finally came home to her adoring family after 2 weeks and has been thriving and healthy ever since.

At 5 months, she was referred to the Central Remedial Clinic for Physiotherapy, which has been going really well. I learned of the Parent & Toddler Group and found it great to talk to other mothers in similar circumstances and to share our experiences. I have made great friends over the past 3 years and thank them all for their support. Sophie is starting pre-school in the CRC in September, so I am now leaving the group.

There is no doubt these last 3 years have been emotionally difficult. They put a huge strain on our entire family, although we all supported each other and have grown stronger as a result. To us, Sophie is just like any other little 3-year old girl. Her favourite past-times are to hand paint and to play with her dolls. She has a great personality and her determination has helped us all over the last 3 difficult years. She has her

splints and walker, and is able to toddle around. Our hope is that she will progress onto a main-stream school.

These last few years have been a leap into the unknown for us, but we have been surprised at how well Sophie has done and how she has blossomed. With all our hearts, we thank the staff at Temple Street and the CRC as without this support there is no doubt we would not be where we are today.

Fionn's Story

'I try not to look too far into the future'

'Is there a history of twins in your family?' the nurse asked. I was 13 weeks pregnant and having my first scan. The question did not register with me at first as I had been nervous and was just so delighted to have seen the baby moving. My husband Jim understood straight away and told me later that he thought he could see 2 heads during the scan. The nurse informed us that I must come back for a second scan at 20 weeks 'just to make sure they are not fighting with each other!' We went home and told all our family and friends our wonderful news.

After several scans and a few alarming moments, I was referred to a twin specialist who informed us that one baby was getting a reduced blood supply, while there was a possibility that the other baby may be getting too much. The babies might have to be delivered prematurely. At week 31, I was having my regular scan when the nurse noticed that the smaller baby's heartbeat was erratic. The baby was obviously in difficulty. The consultant was called and an emergency Caesarean section was decided upon.

During delivery, I looked up at the ceiling and wondered what the outcome would be. When the first baby was delivered they told me it was a boy and I remember thinking that premature boys sometimes have a harder time surviving than girls. My first beautiful little boy, Aodhán, was born on 8th June 2004 weighing just 2lb 5oz. My second beautiful boy, Fionn, was born a minute later weighing 3lb 10oz. I remember hearing them both cry, which seemed a good sign, and seeing each one for a fleeting moment before they were whisked off to the special care baby unit.

As I had had a section I did not get to see the boys until the next morning, but the nurses kindly showed me digital photos of them both so I could look at them during that first night. When I saw them the next day, it was quite frightening. They were so small, so vulnerable, so beautiful and already such survivors. They got through the first crucial 48 hours and things were looking good. However nothing can prepare you for the roller coaster ride of having premature babies.

The boys survived their first week without having to be ventilated and all was well. Three and a half weeks after their birth they were transferred to a hospital closer to home, where they underwent further tests and scans. It was then that our world fell apart forever: we found out that Fionn had Cerebral Palsy.

The day started like any other day, I was up in the hospital visiting the boys when the nurse told me the doctor wanted

to talk to me. The doctor met with my husband and me and gently explained that Fionn had suffered damage to his brain. A scan had shown up abnormalities in the area of the brain controlling movement and co-ordination. I listened numbly not really taking the enormity of the situation in. It was then that the word Cerebral Palsy was mentioned.

I cannot really describe how I felt for that week. Numbness. Heartache. Sadness for the loss of a 'normal' life—Fionn's and ours. The hardest part was that for 4 weeks we thought everything was fine. However, I am thankful for the quick diagnosis so that we could prepare ourselves for what lay ahead.

Fionn weighed 5lb 15ozs when we finally got to take him home eight weeks later. I took Aodhán home a week later, weighing just 4lb 9oz. Their big sister Niamh didn't know what to make of her Mam and Dad bringing home a baby every week! Life was very tough that first year. Fionn was very unsettled. In fact, he didn't sleep a full night for over two years. Both boys needed constant monitoring because of their prematurity. I look back on that first year with sadness as I could not enjoy my babies' development. With Niamh I had taken delight in her every milestone. With the boys it was just: let's get through it. I was and am heartbroken.

The boys are growing fast and although life is still hectic things have settled down—a little bit! I try not to look too far into the future. I don't yet want to think of wheelchairs, hoists and house adaptations. I concentrate on all the

wonderful little things Fionn has progressed in. There are still plenty of times when I have waves of guilt for not spending enough time with Niamh and Aodhán but I thank my lucky stars for the three beautiful, loving children and wonderful husband that I have.

Fionn's condition is severe. All four limbs are affected – he cannot hold anything, feed himself, roll, sit, walk or talk. He basically has the physical movement of a 3 month old baby. His needs are great - a lot of time is spent exercising him, developing his alternative communication skills and bringing him to various appointments. It's a full time job and I doubt that I will ever return to the workforce. However, he appears to be a bright little boy who is very healthy, extremely determined and has a smile that would light up a room. Aodhán is nothing short of a miracle, very independent and is the comic in the family. Niamh is the bright spark, a dynamic, spirited and sensitive little girl who looks out for her brothers.

Having a child with special needs changes you. You mourn for the 'normal' life your child will never have and you mourn for the loss of a 'normal' family life. Your family life comes under so much pressure and is consumed by disability issues. It is stressful and very exhausting and the strain on your marriage can be immense. Alongside this you also have to deal with lobbying for better services for children with special needs and that adds to the sadness. Shouldn't every child have the right to reach their full potential? At times you can feel quite isolated, the forgotten ones, those left behind. On the other hand, it makes you more sensitive to social issues - it pulls

you out of the rat race and lets you become more aware of other people's needs. Children with special needs are individuals in their own right. They should not be an extension of you, or how you feel. If they are happy then you should be at peace. And that is what I pray and hope for going into the future—that all my children will be happy.

Kian's Story

'I realised I wasn't the only one with a child with problems'

When my beautiful son Kian was born in 2005, he only weighed 3lbs 6ozs. He was so tiny they kept him in the hospital, so I went up to see him every day and night.

The doctors told me Kian had three bones missing in his back and that he had Caudal Regression Syndrome, so he has problems with his kidneys and bowels. My little boy also has club feet and his hips come out of place. I was so shocked, I collapsed. It took three doctors to pick me up. I thought it was a bad dream.

Kian started in the Central Remedial Clinic when he was three months old. I was waiting to see his Physiotherapist one day when the Social Worker invited me to join the Parent & Toddler Group. Kian was six months old at that stage.

In the group, I listened to the other Mams talking about their children. I met lovely people who helped me come a long way from where I had been previously. I realised I wasn't the only one with a child with problems.

They helped me through the hard times and to understand how to best deal with Kian's condition. I met people who listened to what I was going through with my son.

I would like to say thanks to everyone in the group.

Luke S's Story

'Such small things gave me so much hope'

Hi all! I would like to start by welcoming you to the Central Remedial Clinic (although you probably don't want to be here right now) and to let you know you are not on your own. You are in the best place for you and your child's needs.

My name is Ann-Marie and I have two sons. I love them dearly and am so proud of them. My youngest boy, Luke, has Cerebral Palsy, epilepsy and asthma.

Luke was born though normal delivery in August 2005, weighing a healthy 7lb. I was so happy to have another healthy baby boy. When he was six months old, he started to do unusual jerks with his hands, and his eyes would fixate up in the air. The doctor told me he had a chest infection and a high temperature, which could be causing the jerks. He prescribed antibiotics for Luke and I was happy.

A couple of weeks later Luke was still doing these jerks, but more frequently and even in his sleep. I knew something was wrong. This time, my doctor referred me to Temple Street Hospital for an EEG scan, which confirmed epilepsy. It never

crossed my mind that anything else might be wrong, but the doctors also said that Luke might have Cerebral Palsy. Next was an MRI scan to confirm this.

This is where my whole world came tumbling down. I was totally shocked and distraught. I felt so angry as I'd had such a healthy pregnancy and had done everything I was supposed to. I just couldn't get my head around it. I was numb for months. I still find it hard to accept.

Luke has Dyskinetic Quadriplegia, which means his four limbs are affected, but the right side is worse than the left. The Neurologist showed me the MRI scan and explained it to me. I will never forget it. He referred us to the Central Remedial Clinic for Physiotherapy, Occupational Therapy, Speech Therapy and anything else Luke needed.

I have to admit, it was horrible walking in to the Central Remedial Clinic for the first time with my beautiful baby boy. It broke my heart. I just could not believe I was there with him; I didn't want to be. What really helped me get used to it were the results I was already seeing in Luke. When he first started Physiotherapy, his right hand was always clenched and he never used it. But he was starting to use it slowly but surely, and it was great to see. Such small things gave me so much hope.

The Social Workers in the Clinic told me about the home respite service, which has been a great help, and about the Parent & Toddler Group. I started to go to the group and have never looked back. I've got to know some amazing mothers

who helped me so much. I'm good friends with them and we talk about everything, whether it's good or bad. We share our ideas and even have a laugh.

The children enjoy it so much too. They get to mix and play with each other, sing songs and even go on outings. The Social Workers and respite workers are amazing. They're so friendly, caring, supportive and understanding. They'll help with anything they can, such as getting information, giving a shoulder to cry on or being there to talk to. I am very grateful for the help and support they've given me.

During group sessions, others sometimes come in and talk to us, such as a Dietician to advise us about our children's nutritional needs and Physiotherapists to show us the best way to lift our children so we don't damage ourselves. I've learnt a lot from the group. I now feel I'm not on my own. I'm not the only person trying to deal with finding out my child has a disability.

Luke is soon starting pre-school in the Central Remedial Clinic and as I move on to another chapter of my baby's life, I'm really going to miss going to the group.

I would like to say a very big thank you to the Social Work team and to the other mothers for everything they have done for me.

Lucy's Story

'A new journey was about to begin'

It was a fine October morning in 2007 as I sat in complete bliss on the number 38A bus heading into my antenatal appointment in the Rotunda hospital. I was feeling on top of the world, 5 days into maternity leave, and was expecting a baby girl the following week. I was full of dreams and hopes of how life would be great with my two little girls. I already had a little girl, Emma, who was 5. Thoughts of my two little daughters running around together holding hands, playing with their dolls, preoccupied my mind. Life was almost perfect. I was on the path to my perfect life, taking big footsteps there all the way. Or so I thought.

I was only inside the doors of the hospital and Baby Lucy decided she wanted to arrive. She was born after a very fast 2 hour labour. I cannot quite describe the uneasiness that I felt as soon as I saw her. She was unusual looking with a thick mop of black hair. My fears were confirmed the moment I got to hold her. She was limp in my arms. Something was not right but the midwives reassured me all was well and a

consultant confirmed she was fine.

I didn't sleep that first night. All the other babies were wailing but my baby remained silent—a very uneasy silence that made me feel uncomfortable. She was 2 days old when a Professor in the hospital confirmed my worse fears. Lucy was not the same as other babies and tests were ordered. I was so lonely in the hospital. Everybody else had perfect babies and I was at the beginning of a totally different journey that I neither wanted nor expected. I also knew that I would be doing the journey on my own with my 2 little girls.

By 6 weeks old, Lucy was already behind in her development, but nobody seemed to notice. They were all transfixed by her big mop of dark hair. But I was stuck in a horrible place. I didn't feel like a new mum and just went though the motions fulfilling all of Lucy's needs. When people commented on her lovely hair, all I could see was a disabled baby. I just could not see past the fact that my child was different.

In the next few months I met numerous doctors, consultants, neurologists. I soon knew every chromosome in the human body, what words like Hypotonia and Laryngomalacia meant. Google became my best friend but also my own worse enemy. I ran up 19,000km on my car driving to appointments and was soon on first name terms with the local car clamper.

Lucy was 10 months old when I first walked though the doors of the Central Remedial Clinic. A new journey was about to begin. As Lucy had no diagnosis, I felt like I was no longer out in the rain with nowhere to go but finally at a place where I

would get answers.

Lucy had a team of people looking after her. Each of them did amazing work. Her Physiotherapist really got to know her and got the best out of her. A consultant gave her the most though examination she has ever had and was always willing to see Lucy or discuss any issues we were having. There were many appointments, including the feeding clinic and a hydrotherapy programme. I joined the Parent & Toddler Group and greatly looked forward to these weekly meetings. I could not have imagined that my child's disability would have allowed such amazing people to cross paths with me and enrich my life so much. There were plenty of tears, laughter and fun—not forgetting the tea and biscuits.

It became apparent that Lucy had intellectual difficulties as well as physical problems, and I felt I was back at the crossroads again. A Psychologist assessed Lucy to determine the best learning environment for her. I understood that Lucy would be moving to a service for children with intellectual disability, but her stubborn and determined nature sparkled and she did well in her assessments. I was particularly impressed with the physiologist who gave Lucy every chance to shine when even I had given up.

Today Lucy is a wonderful little girl who loves to do normal toddler activities. She doesn't speak, but communicates through sign language and play. I no longer see disability. Instead, I see a hilarious little toddler who is always smiling and up to mischief. She loves to play with her dedicated big sister Emma.

Lucy will be starting preschool in the CRC and it will be a huge transition for us.

Every morning I wake up to two smiling little girls and I realise that these are the important things in life. I might not be on the journey that I planned, but although we can't change things, we can change how we deal with them and take each day as it comes. Lucy's smile says a thousand words.