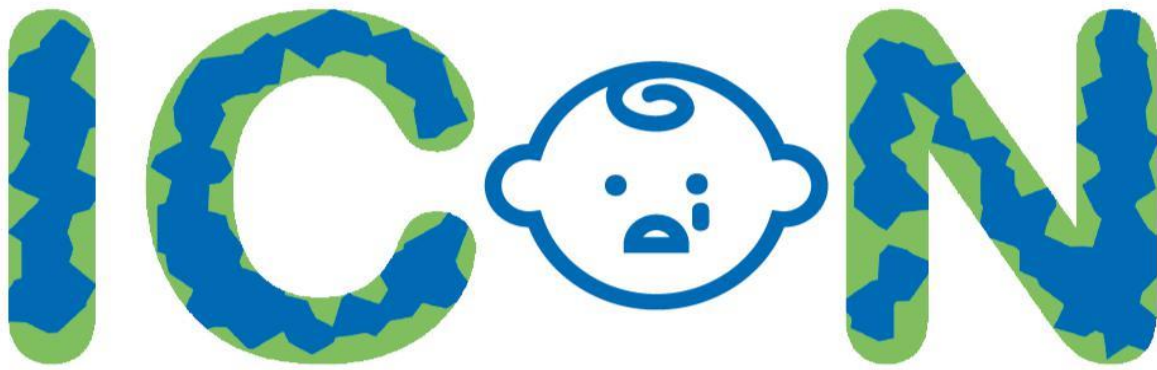


NEWS UPDATE



Babies Cry, You Can Cope

SEPTEMBER 2020 SPECIAL EDITION

September's newsletter is a special edition... from Parents, Aunties and Siblings of children that have been injured as a result of being shaken.

MESSAGE FROM Mae Pleydell-Pearce, ICON Parent and Families Representative

We feel very privileged to be part of the ICON journey, many of us starting at the very beginning.

Speaking on behalf of all of our parents in the support group Charlees Angels, we can all feel a small sense of peace and acceptance that through our children's stories and with all your professional help, we can stand united and provide a programme that not only supports parents, allows professionals to really engage with new parents and most importantly saves babies from suffering, the way our children have suffered.

A very big thank you to each and every one of you that go that extra mile and really champion ICON in every aspect of health care.

ICON is so wholesome and we are lifted by being part of the journey.

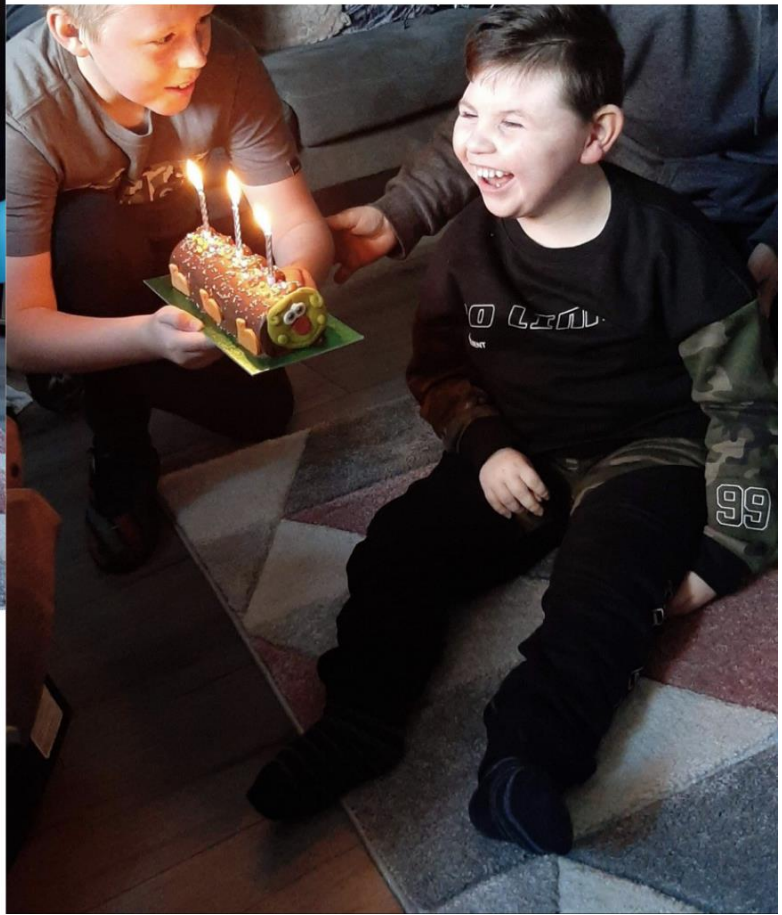
Mae



Meet Charlie, age 13, when he was 15wks old we didn't think he was going to make it through the night, then I was told he may never walk or talk. He has cerebral palsy, learning/behaviour difficulties and is blind. Charlie always has a smile on his face (except when he's been a moody teenager) he can walk aided/supported and talks for England! He likes to sing and dance and loves going to school , he has a cracking sense of humour and loves to tell jokes. Life can be tough but Charlie brings so much joy to our lives and everyone he meets, he really is an inspiration.

Charlie and Joanne

"I still have to pinch myself and check ICON is real sometimes. Im so proud to be part of it, it means so much to myself and my family.. we also have an extended family now thanks to ICON."



Hi, my 2 boys, Kieran(11) & Jason(6), celebrated their birthdays this past week. Kieran's birthday is always filled with fun, laughter and watching him opening up his presents but with Jason's, there always feels like there is a dark cloud hanging over it, as he cant just simply rip open his presents & tell us how excited he is, although we still always celebrate the best we can. But this year was different, things felt light and there was a warm glow around it all. Yes he still can't tell us how excited he is or how much he loves his gifts but there was just so much joy on his face. He got a sensory den from his grandparents and it's the best thing ever, it helps relax him so much and something we can all enjoy together as a family. Things like this are so rare after what was taken away from him, but every day we are building on the positives and we get stronger with them. Jason was shaken at 5 weeks old but every single day he amazes us with his achievements, no matter how small. He's our very own little superhero

Laura, Kieran and Jason

"ICON means so much to myself and my family. Knowing we can turn a negative life changing event into something positive, is what we wanted. I'm so proud to be apart of it."



Jacob is now four, a victim of Shaken Baby Syndrome at the hands of his biological father at 5 weeks. He is doing very well despite his injuries and we take every day as it comes. He is a cheeky, happy, kind and caring little boy. As a result of his extensive brain damage he has cerebral palsy, global development delay and a speech impediment. He is a very aware and sociable. I do worry how he will come to terms with his story one day, but I will always ensure this is done a child focused way.

This year he has started having seizures. This has not happened since 5 weeks of age, when he was placed in a medical coma after his injury. Being a nurse I should be able to manage this but when it comes down to being your son that is suffering it breaks your heart and you feel lost.

Jacob started his new school this month. He is starting mainstream school and has been awarded one to one support. We have put him back a year due to his development delay to help give him a better start, so he will be in nursery first. I am so proud of him and how much he has achieved. He was so excited about his first day but when I picked him up he looked sad, I could not find out why. I asked him questions, I gave him pictures to try and express himself, but he could not explain why he was feeling sad due to his struggles in communication. It dawned on me that the other children would be telling their mummy's and daddy's about their day. I felt overwhelming sadness for Jacob.

Jacob has had a hole filled in his heart by my partner, who he calls Daddy. We have been blessed with an additional member, who will be with us in 5 months! Jacob is very excited by this. I do worry that his sibling will reach the milestones before Jacob is able to reach them and how this will affect him. I know our journey will always be full of learning, but also of happiness, love and hope .

Jacob & Heather

"ICON has saved lives. It has given empowerment to victims. To treat is to prevent. Education is knowledge"



Hi i'm Rio, I'm Ellis's brother. I'm a huge fan of musical theatre and I do a theatre class on a Saturday. I also work doing theatre before my class with the younger ones and getting paid. I love to sing and I love to do creative things. ICON is a great programme to get the message out to every parent.

" I miss Ellis every day, and hope ICON can prevent babies being shaken , and brothers being taken away as Ellis was.



Mae

"ICON means so much to me. It's helped to fill such a sad loss. Ellis's story on the ICON website is intended to inspire and motivate and tell the true facts. I'm so grateful that the knowledge of his suffering is being used to help ICON save babies all over the UK. Thank you"

Harvey enjoying his 16th birthday celebrations



My son Harvey was turning sixteen this year, and I wanted to do something special. I got thinking that over lockdown we sent postcards and letters to his friends, he loved having some returned and I remembered his love for birthday cards, each birthday they would hang around our house and we would read them aloud. So, I had an idea for a birthday card appeal.

Harvey loves telly programmes, mostly cartoons but has lots of favourites, mostly silly, naughty or just funny. He has an outgoing personality and a very social young lad. He loves a party or any social gathering. Which has been sadly become impossible lately due to COVID.

On the 1st of August I wrote a post on Facebook, saying it was Harvey's 16th on the 31st August and he would be over the moon if you could send him a birthday card. Then to our shock each day afterwards we received birthday cards for him in the post, which we kept in a pile, which grew and grew.

The morning of his birthday the four of us spent ages and ages opening them, laughing at the pictures. Harvey had some from different states in

America, England, Scotland and from here in Wales.

Our living room has been a sea of cards, which has honestly been so lovely. Friends have been so kind by helping and giving cards. This kindness is genuinely appreciated as it approaches the shaken anniversary. Which year after year this brings a new mix of emotional trauma, more so with milestone birthdays.



Harveys birthday card appeal was amazing, he was so lucky and was given 156 birthday cards. 18th birthday is the next big one, hopefully we can have the biggest party ever!

Sarah and Harvey

"ICON has been a positive way of spreading awareness"



"From day one - support and input from the family steering group has been fantastic.

I'd like to personally thank you all because this information has been pivotal to help Sue create ICON, which she and her team have done with such emotion, passion and dedication and I'm sure that can be felt by us all. It's every bit and more than what I had hoped for-unfortunately for us- we had nothing like this through our circumstances- however isn't it something that we have played a part in preventing AHT in the name of our loved ones"

Jess Stephenson- founder of Charlee's Angels



Any questions or comments to:

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