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Hello and Welcome

Welcome to Renal Agenesis UK's newsletter.

Who are we?

Renal Agenesis UK was launched on 11th January 2019 after our founders Gillian and Lawrie lost their son, Jacob, following a Bilateral Renal Agenesis diagnosis in January 2014.

After Jacob died, both Gillian and Lawrie felt lost. There was basic factual information about Bilateral Renal Agenesis on the internet but there was no signposting to support charities such as ARC (Antenatal Results and Choices) or Sands UK and Gillian was unsure if they would support her given that she and Lawrie had had to make a decision about stopping Jacobs much wanted pregnancy.

Through their grief, Gillian and Lawrie began thinking about setting up an organisation which would support parents and families whose child who had a diagnosis of Bilateral Renal Agenesis. A place where parents could come together and where everyone just knew. They knew what it felt like to hear the words Bilateral Renal Agenesis, they knew what it felt like to be told that their baby was going to die, they knew what it felt like to have to make a decision about their precious baby’s pregnancy, either terminate for medical reasons or continue with the pregnancy, with both options sadly having the same outcome, the loss of a much loved and wanted child.

Renal Agenesis UK started out as a social media page but it has grown over the last few years into a registered charity with an information leaflet, virtual support group and a board dedicated in raising awareness of this condition and the devastating affects of losing a child.

What is Bilateral Renal Agenesis?

Unless you have had or know of a child who has been diagnosed with Bilateral Renal Agenesis, many of us will never have heard of the condition.

So what is Bilateral Renal Agenesis?

Bilateral Renal Agenesis is when both kidneys fail to develop during the early weeks of pregnancy.

Most people have 2 kidneys, one on the left side of the body and one on the right, which along with the bladder, ureters and urethra make up the renal/urinary system. This is a system which essentially eliminates waste from the body in the form of urine.

However the renal system has other important functions including regulating the volume of blood in the body, regulation of the blood pressure, and balancing blood PH levels which stops the blood becoming too acidic or too alkaline.

And finally the renal system helps to control the level of natural salts, called electrolytes, and metabolites, which also occur naturally in the body.

All these functions keep our blood and body in a state of balance every day.

Bilateral Renal Agenesis is when both kidneys fail to develop but sadly it is not usually picked up until a 20 week anomaly scan.

There is a reduction in amniotic fluid called Oligohydramnios, where there is too little amniotic fluid around the baby or Anhydramnios which is a complete or near complete absence of amniotic fluid present, which is usually noted first.

Reduced amniotic fluid volume is usually an indicator that there is a problem with the development of the kidneys.

In the case of Bilateral Renal Agenesis, the kidneys have completely failed to develop during the early weeks of pregnancy.

During early pregnancy it is a mothers body which will produce amniotic fluid. But usually from around 14-16 weeks the baby will begin to swallow the amniotic fluid and, in the presence of kidneys and a renal system, will then pass the fluid out as urine and this continuous cycle which keep going until the baby is born.

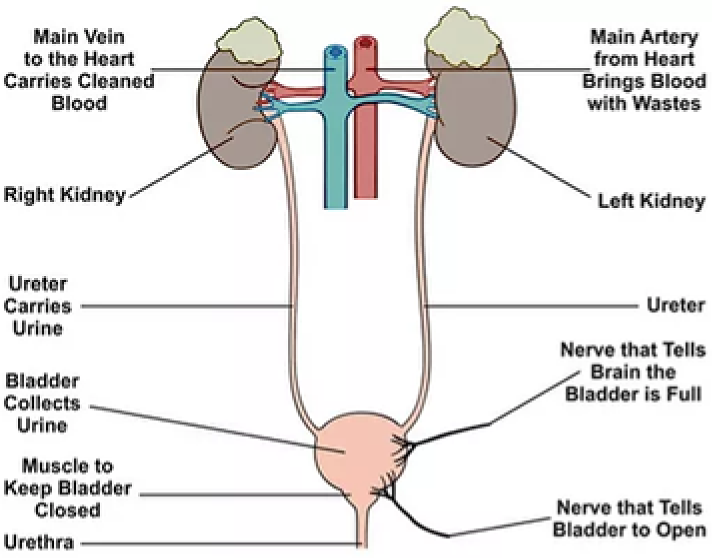
During pregnancy a baby’s lungs are filled with amniotic fluid which creates a positive pressure in the baby’s developing lungs, and this pressure enables the lungs to develop, grow and mature ready for birth.

In cases of Bilateral Renal Agenesis, any fluid swallowed will be absorbed by the baby and the placenta replaces the missing kidneys in filtering waste out of the baby’s blood

With there being very little or no fluid remaining, there is not enough fluid in the baby’s lungs to help develop them resulting in a condition called Pulmonary Hypoplasia.

Pulmonary Hypoplasia is when a baby’s lungs are too small and they do not have enough tissue and blood flow to enable the baby to breath on their own.

Sadly baby's will pass a few precious minutes or hours after birth



Virtual Support Meeting

Thursday 16th March 2023 at 7.30pm

We held a trial support group in May 2022 which was well attended. It was a lovely informal space where parents could come and share about their child and their experience if they wanted too.

There is no pressure for anyone to share, the group welcomes those who just wish to sit and listen to others.

We are delighted to announce we will be holding a quarterly online support group with the first group being on Thursday 16th March 2023 at 7.30pm.

If you would like to attend please send your name and email address to support@renalagenesis.org.uk and we will send you a link to the meeting.

We meet using the Microsoft Teams platform at Renal Agenesis UK, the link may seem long but due to data protection, we cannot currently input everyone's email address into an open email and Microsoft Teams currently does not have the facility to blind carbon copy (bcc) but rest assure that the link will work and admit you to the virtual support group.

We look forward to welcoming you.

Join Us

If you would like more information or are considering joining the Renal Agenesis UK Board as a charity trustee please email enquiries@renalagenesis.org.uk, you would be most welcome.

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