Special News

Spotlight on Downs Syndrome

Meet Vincent

Meet Cara

Introduction to the nursing team within Ivy House School

Day in the Life of Louise J

Focus Page on Foetal Alcohol
‘Special News’ 2 From the Disabled Children’s Nursing Service

Welcome to our second newsletter which aims to aide communication across our busy services raising awareness of Disabled Children’s issues through information, updates, introductions, and by enabling signposting.

This half term’s ‘Special News’ is larger than the first, as I am delighted to have guest reporters introducing themselves, their work and their little ones to us.

We have a ‘focus’ on FASD, and also a ‘Spotlight’ on children and young people who have Downs Syndrome. We also have articles in regards to continence booklets, free health checks and makaton.

A big thank you to all who completed the feedback sheet and emailed this back, some extremely positive and valuable information was gained. It would be really helpful if you could spend a moment to feed back on this newsletter too, please see the second attachment.

Janet

So what’s in Special News 2?

✅ Introduction to the nursing team based at Ivy House School

✅ Page focus on Foetal Alcohol Spectrum Disorders
Introduction to the Nursing Team based at Ivy House School

Ivy House School is a special school in Littleover. We have 84 pupils ranging in age from 2 and a half to 19 years. All of the pupils have some form of special needs and many of them require specialist medical care throughout the school day.

The nursing team comprises of Katherine Raven, lead nurse, Kerrie Bingham, registered nurse, Shelley Carpenter, band 4 assistant practitioner, Annie Cooke, band 3 assistant practitioner and Shelley Foster, band 3 assistant practitioner.

Every day we complete a wide range of approximately 100 regular medical interventions for the children including Gastrostomy feeds, naso-gastric feeds, medication administration, intermittent catheterizations, tracheostomy care, emergency epilepsy care, first aid and many assessments. Our aim is to ensure that any child, regardless of the complexity of their needs, can access education and has the same opportunities as any other child. This may mean training class staff to carry out...
tracheostomy suction within the classroom, or supporting children with airway management whilst on school trips.

In addition to the regular interventions our team carries out we also run four doctors clinics within school a month, carry out continence assessments, plan for care in the community alongside other agencies, work alongside other agencies in safeguarding, offer advice to parents on any aspect of their child’s care and refer families to other agencies who can help them.

Ivy House is a wonderful place to work due largely to the amazingly courageous children we work with. Given the support of our team and the highly skilled education staff the children thrive.

Some of our favourite moments are when our children achieve what was thought to be impossible. For example seeing the child who was told they would never walk independently, walk unaided down the corridor to a family who never believed it could happen. Hearing a child with no communication skills, access a specialist computer in order to make a sentence for the first time. These children who have never had a voice then go on to chat and chat with specialist computers. In fact one young man who uses such technology was heard, when introduced to a previous chief executive of the trust, to say “I know your bum is big but right now it’s in my face”. One of the more embarrassing days.(Photo of the team and of a happy little man enjoying play – Thanks mum for saying yes to show his picture)

Katherine Raven - Lead Nurse, within Ivy House School

Foetal Alcohol Spectrum Disorder
What is FASD?

FASD, Foetal Alcohol Spectrum Disorder is an umbrella term for several diagnoses that are all related to prenatal exposure to alcohol (i.e. while a baby is still in the womb)

These are:
- Foetal Alcohol Syndrome, FAS
- Partial Foetal Alcohol Syndrome, PFAS
- Alcohol Related Neuro-developmental Disorder, ARND
- Alcohol Related Birth Defects, ARBD
- Foetal Alcohol Effects, FAE

FASD is a series of preventable birth defects caused entirely by a woman drinking alcohol at any time during her pregnancy, often even before she knows that she is pregnant. Beer, wine, spirits - it's all the same to the developing baby.

The term "Spectrum" is used because each individual with FASD may have some or all of a spectrum of mental and physical challenges. In addition each individual with FASD may have these challenges to a degree or "spectrum" from mild to very severe.

Common problems include:
- Vision impairment
- Sleep problems
- Heart defects
- Liver problems
- Poor immune system
- Speech & language delays
- Impulsivity
- Memory problems
- Hyperactivity
- Inappropriate social behaviour

These defects of both the brain and the body exist only because of prenatal exposure to alcohol. Often the condition goes undiagnosed, or is misdiagnosed, for example as Autism or ADHD, and this can lead to secondary disabilities.

How many people are affected?
The incidence of FASD in the UK and internationally is not accurately known. Many children born with FASD are not diagnosed, or do not receive a correct diagnosis, which makes calculating the prevalence of the condition extremely difficult. International studies and the World Health Organization indicate 1 in 100 children are born with FASD worldwide. With the high level of binge drinking in the UK it is possible that this number may well be underestimated. (Info. used from the FASD trust website Dec. 2015)

The FASD Trust - The FASD Trust was founded in 2007 by Simon and Julia Brown to provide support for those affected by FASD and training / information for the professionals seeking to support them. The FASD Trust runs support groups for those affected by FASD across the UK, hosts various professional forums and has a variety of training and other resources for those affected by or interested in FASD.

Tel:01608 811599  www.fasdtrust.co.uk

Classical News 2  February 2016  Janet Beasley
Children’s Continence

Thanks to Sue Walker – Senior Nurse Children’s Continence

- Do you see children who have yet to be toilet trained?
- Or have problems with wetting day or night time or constipation?

Most children with learning disabilities, including Down syndrome and communication disorders, such as Autism, have the ability to become continent. These children will have the same physical development as their peers in relation to their bladder and bowels, but struggle to make the connection with the feeling of a full bladder or bowel and the need to go to the toilet. Therefore it is important that all professionals encourage all children to start toilet training from the age of 2.

There is lots of simple information you can give to parents around routines, good drinking which will promote continence. For further information and leaflets you can print off for parents go to http://www.derbyshirehealthcareft.nhs.uk/services/childrens-services/continence-nursing/continence-packs
**Free Annual Health Checks for Disabled Young People at their GP’s**

Did you know that from April 2014 young people aged 14 – 17 years who has been assessed as having a moderate to severe or profound learning disability, or people with a mild Learning Disability who have other complex needs, are entitled to a free annual health check at their GP’s surgery?

These health checks came about after a Confidential Enquiry into premature deaths of people with Learning disabilities (CIPOLD).

The inquiry found that three times as many people with learning disabilities die before the age of 50 compared to the general population.

“Young people of 14-17 years with learning disabilities are recognised as being particularly vulnerable to issues around their health and these changes aim to help the transition from children’s to adult services. Particularly if parents aren’t strong advocates for them, this is a time when healthcare needs can fall between the cracks. A truly joined up effort will be needed to ensure that we are successful in helping these young people.”

GP practices are now being paid for the health checks on a quarterly basis.

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**Communication**

**Makaton** is a language programme using signs and symbols to help people to communicate. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order. With makaton, children and adults can communicate straight away using signs and symbols.

Within each newsletter we will spotlight three makaton signs which may assist you when supporting people who use this method of communication, alongside speech.

Always ensure the child / young person or adult can see your hands and say the word clearly at the same time.
Special News 2        February 2016               Janet Beasley

Meet a member of our team

A day in the life of Louise Jenkins

Clinical Senior Nurse, Disabled Children's Nursing Service, Base Cardinal / Lighthouse

Source the Makaton Charity website
I have chosen this particular day because I feel it shows how the Clinical Lead post is quite varied and everyday is different, that’s one of the reasons I love my job and enjoy new challenges.

This morning I started the day at 7 at the Light House, I worked with another nurse and social care staff to get 5 children ready for school on Sun unit. I had to wake one of the children as he was snoring away and loving his bed! He has quite a regime with medication and feeds so I slowly encouraged him to start his day, I was greeted with his amazing smile when he woke.....It was a busy morning but we managed to get all the kids ready before their transport arrived. We had a tidy up and documented in the children’s notes.

I then went up to Chesterfield Royal Hospital to the Medicines Safety Committee; we discussed topics relating to the trust and feedback for the recent pharmacy audit that took place. This then enabled me to action, and arrange time with Emma from pharmacy, so we can look at storage of medicines within the Light house and Special Schools.

I then headed back to the Light house to open my e-mails and responded to a couple of alerts through DATIX which is where we record incidents.

Just after lunch I headed off to Ivy House School to meet the Nurse there as we have developed a tracheostomy training pack, we spent time with one of the young people to establish a set protocol for what we need for completing a tracheostomy tube change. I then completed the tube change for this young person and let another member of staff observe with the view that they would complete next week. The young person was so relaxed and coped well with the change. I contacted his mum just to let her know he was fine with the tube change and thanked her for letting staff have this opportunity. I then spent time with the Nurse at Ivy planning the next staff to complete the changes for their development.

Today has been a productive day, great to work with the young people and also meet / network with others from the trust.

Off to face the school traffic now and dart across town!!

Louise can be contacted on - 01332256997 louise.jenkins@derbyshcft.nhs.uk

Meet Vincent!

...our adorable 7 year old son, a happy, cheeky chappy who loves life :)

Vinnie has Downs Syndrome and a slight hearing impairment but that doesn't hold him...
back. With a great 'I can do' attitude he loves to try anything his big brother Max does, like swimming, bike riding, trampolining, gymnastics, football, playing endless games on the Xbox and I Pad and taking cute selfies on my mobile phone when I'm not looking!!

His favourite films are all the Harry Potter movies and Scooby Doo, he loves all animals, especially cats and dogs.

Vinnie is loveable and relishes in hugs, kisses and snuggles. He loves positive attention, has a brilliant sense of humour and a very infectious giggle. He reaches his milestones steadily but surely and loves learning and socialising with all his friends at school.

We are sooooo proud, blessed and privileged to be his Mum & Dad and to call him our son xx
Causes of Down's syndrome

Down's syndrome is a genetic condition that occurs as a result of an extra chromosome (chromosome 21).

Chromosomes The human body is made up of cells that contain genes. Genes are grouped in thread-like structures called chromosomes.

Chromosomes are blocks of DNA and contain detailed genetic instructions responsible for a wide range of factors, including:

- how the body's cells develop
- the colour of the eyes
- the sex of a baby

Usually, cells contain 46 chromosomes. A child inherits 23 from the mother and 23 from the father.

In people with Down's syndrome, all or some of the cells in their bodies contain 47 chromosomes, as there is an extra copy of chromosome 21. The additional genetic material causes physical and developmental characteristics associated with Down's syndrome.

Types of Down's syndrome

There are three forms of Down's syndrome, although the effects of each type are usually very similar.

- **Trisomy 21** is the most common type, affecting around 94% of people with Down's syndrome. It's where every cell in the body has an extra copy of chromosome 21.

- **Translocation** is where an extra piece of chromosome 21 attaches itself to another chromosome. It affects around 4% of people with Down's syndrome. In this situation, there are only 46 chromosomes in each cell but one of them has extra material attached, so the total amount of genetic material in the cell is similar to that seen in a trisomy.
Mosaicism is the least common type, affecting around 2% of people with Down's syndrome. Only some of the cells have an extra copy of chromosome 21, which can mean people with mosaic Down's syndrome experience less delay with some aspects of their development.

In the vast majority of cases, Down's syndrome isn't inherited, and is simply the result of a one-off genetic mistake in the sperm or egg.

However, in some cases caused by the translocation of chromosome 21, the genetic mistake is passed on from one of the child's parents, even if they have no signs of Down's syndrome.

**What are the chances of having an affected pregnancy?**

With every pregnancy, there is a small chance of having a child with Down's syndrome.

There's currently no clear evidence to suggest that anything done before or during pregnancy increases or decreases this risk, although some people are more likely to have a child with Down's syndrome than others.

The main factor that increases the chance of having a baby with Down's syndrome is the age of the woman when she becomes pregnant. For example, a woman who is:

- 20 years of age has a risk of one in 1,500
- 30 years of age has a risk of one in 800
- 35 years of age has a risk of one in 270
- 40 years of age has a risk of one in 100
- 45 years of age has a risk of one in 50 or greater

However, babies with Down's syndrome are born to mothers of all ages.

The chance of having a child with Down's syndrome is also increased if you have previously had an affected pregnancy. For most people this risk is still small (around one in 100), although this may be as high as one in 10 if you or your partner have the altered genes that can lead to the translocation of chromosome 21.

There is around a one in two chance of a child having Down's syndrome if one of his or her parents has the condition. (NHS Choices information uses for this article).

**Although babies with Down syndrome can be just as healthy as any other children, they can also have health and wellbeing problems. Even though some of these problems can be quite serious, the good news is that medical treatments have improved substantially, and the vast majority of babies and children with Down syndrome grow up healthy and active.**
Some of the health issues that have a higher incidence for children / people who have Down’s syndrome

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<tr>
<th>Visual Impairment</th>
<th>Mental Health / Neurological</th>
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<tr>
<td>Around 70% of children with DS will have some type of vision problem-need for regular screening prompts.</td>
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<td>At least 50% of children and adults with DS will face a major mental health concern during their life span. Children with multiple medical problems, experience even higher rates of mental health problems.</td>
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<td>Studies suggest that between 60 - 90% of children have some hearing impairment.</td>
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<td>There are links between DS and ADHD, and Autism.</td>
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<td>Studies suggest that 10 - 27% of individuals with DS have evidence of increased movement at the cranio vertabral junction.</td>
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<td>Also 10% of children with DS have Epilepsy.</td>
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<tr>
<th>Cranio vertebral Instability</th>
<th>Upper respiratory problems</th>
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<td>Studies suggest that 10 - 27% of individuals with DS have evidence of increased movement at the cranio vertabral junction.</td>
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<td>Higher likelihood of respiratory infections</td>
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<td>Hypertonia of muscles, and joint hypermobility is a result of abnormalities in chromosome 21.</td>
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<td>Sleep apnoea - mouth breathing, snoring, enlarged tonsils</td>
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<td>Only 7.4% of adolescents with DS meet recommended levels of physical activity and the % of adults is 0%</td>
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<td>Higher incidence of dental problems</td>
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<td>Discuss and refer to OT, Physio or for diet / exercise advice</td>
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<tr>
<td>Discuss or Refer for GP, respiratory clinic, speech and language therapy, or for Sleep studies. Regular dental checks required.</td>
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<th>Heart Defects</th>
<th>Weight issues</th>
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<td>Between 40 - 60% of babies who have DS have congenital heart defects.</td>
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<td>Around 44% of People with DS are obese.</td>
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<td>Observe for breathlessness, facial colour change etc. and discuss with parents and refer as required.</td>
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<tr>
<td>A regular need for height / weight checks and dietary / exercise advice as required.</td>
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<th>Thyroid</th>
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<td>Around 10% of the school age population have uncompensated hypo thyroidism the prevalence increases with age.</td>
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Specialist services (DHCFT) for pre-school children with Down syndrome

Who are we?
We are a small team based at the Ronnie McKeith Children’s development Centre (CDC) at Derbyshire Children’s Hospital. We are: Consultant Community Paediatrician Dr Sarah Hobday, Senior Health Visitors for Disability Sally Neely and Narinder Ghei, and Physiotherapists Clare McQuilton and Penny Chambers. We also have access to Occupational Therapy and Speech Therapy colleagues and liaise closely with Early Years Education colleagues.

What do we do?
We receive referrals about new born babies with diagnosis of Down syndrome mostly from the hospital paediatricians. We generally expect to have about 6 – 8 babies born a year with Down syndrome in South Derbyshire. Universal health staff can refer children in if they seem to have been overlooked or perhaps moved into area. Please contact us if you think you have found a baby who has been missed.

We offer an initial joint home visit with the community paediatrician and senior Health Visitor as a first appointment for new born babies. Families vary enormously in the sort of questions they have at this stage. We can provide information on Down syndrome and sources of support. After this they will be seen in clinic at the CDC and we have a “drop in” clinic bi-monthly where parents can just turn up to see any of the team or just enjoy a chat, a play and a cup of tea with other families.

What is it like to have a baby with Down syndrome?
About half of babies born with Down syndrome also have congenital heart disease. This can be very serious. There is a particular form of congenital heart disease associated with Down syndrome called AVSD, or atrioventricular septal defect which basically means the very centre of the heart is not properly formed. Down syndrome can also be associated with other physical congenital abnormalities e.g. Duodenal atresia (obstruction of the duodenum) and Hirschurngs (obstruction of the lower bowel). Babies born with these sorts of physical problems may have frail health and require hospital treatment and /or surgery at birth or within a few months. Many families in these situations feel that the Down syndrome is the least of there worries.

However for families where the baby is generally fit and healthy we can usually reassure parents that caring for a little baby with Down syndrome is not very different in most cases to caring for any infant and families can get on with enjoying their baby. As they grow delayed development becomes evident and we will monitor this at clinic appointments and home visits and provide further advice. Children with Down syndrome have delayed gross motor skills associated with hypotonia (tendency to floppy muscles) and benefit from physiotherapy. They also particularly struggle with speech and language and benefit from introduction of early signing - all our families love Mr Tumble!
All children with Down syndrome should have regular health checks including hearing and eyesight tests and screening blood tests for conditions that are common in Down syndrome. In Derby we follow national protocols for health checks (if you want to find out more have a look at www.dsmig.co.uk). Sometimes if the child has complex health problems their care will be shared with the hospital paediatrician and other specialist doctors such as the cardiologist.

We really love our work with this group of patients and their families. If you ever want to come along and visit us or have a query please get in touch tel 01332786727. One of our parents has written about what it is like to be a parent on this journey so please read on……

Meet Kara (Shared by mum Sara)

Hello…My name is Sara and I am a mum of a healthy and happy two year old who likes to try and climb up stairs if she has discovered the stair gate open and loves to play with her little friends at nursery. She has now discovered the joys of the film Frozen and insists on wearing a Frozen dress because her five year old sister has the flashing shiny one which also sings. Kara is learning to walk and talk. I think she has learnt the word no but not why yet. Her sister makes up for that. Kara has Down syndrome which we found out prenatally.

We had this information after the nuchal scan and a blood test. We were told that the possibility was one in five and we elected to have an amniocentesis. This was a hard tough decision that was not made lightly. The fetal medicine team was fantastic and provided us with support and kindness. We were offered impartial advice and when we were once very upset at our treatment at another hospital they respected and listened to us. With the new prenatal test there is a worry that parents will not get the right information. I just hope all parents get the support we have and had with Kara. I hope that it will not result in a cost cutting measure because everyone deserves time and space to make their decision with the right information.

Kara was born a healthy happy baby despite concerns about her heart. She was breastfed, weaned and went as many of the baby groups that you can manage with a three year in tow. As a parent there are tough times but on a regular basis Kara is just a typical toddler. We have done baby signing and that has really been an amazing help. There are some great charities out there such as Umbrella and Derby Down Syndrome. Every child with Down syndrome gets a Portage worker (from education) and we have had excellent Portage workers both from the city and the county. We also attend the Therapy group on the Ronnie Mckeith Centre where we can see the physio, pediatrician and specialist health visitor who have been very helpful and supportive. It’s a nice group and you make friends.
Kara has been at a mainstream nursery since she was ten months, as I returned to work, and she really loves it. She has not needed any special equipment and they treat her as Kara. Many mums do return to work after having children with Down syndrome and there are some excellent providers of nursery care. Before I had Kara I did not think I would be able to work or lead a normal life. Tomorrow we have a farm trip in the morning followed by ballet. I don’t think it’s very different from any other family.

As a parent you just want your child to be accepted as any other child. One of the worst things is to be made to feel different just because Kara had an extra piece of DNA. I think that as a parent simple steps make all the difference. Possibly books in the playroom which have signing or Mr Tumble in them. There are differences in Kara’s development and as she grows older there will be new challenges to meet but this is what they are - challenges. They are not barriers; they are not insurmountable just different ways of learning and growing. To any healthcare professional I would say you all do an amazing job and just treat any child as a child and the parents will be happy.

To our guest reporters…

Vinnie’s mum Lisa

Kara’s mum Sara

Katherine Raven

Louise Jenkins

Dr. Sarah Hobday

Sue Walker

Hope that you have enjoyed reading Special News 2

Now once again I would be really be grateful if you could email me back your thoughts on the feedback form.
**Special News 4** – page focus on **Oral Healthcare** and spotlight on **Autism**

Whether you are a child, parent, carer, a family, student, charity, association or other professionals we would be very keen for you to share your thoughts, from a paragraph to a page etc. The closing date for articles to be submitted for ‘Special News 3’ is April 10th 2016 please feel free to contact I am based at Cardinal Square 01332 888080 ext. 88337 Janet Beasley or email janet.beasley@derbyshcft.nhs.uk

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**Good bye for now… Janet**

Feedback sheet on Special News 2  Tell us what you think?

(1 means - no or not / and 5 being Yes very much)

Did you enjoy reading Special News?

1 2 3 4 5  Comments.................................................................

Have you learnt anything new?

1 2 3 4 5  Comments.................................................................

Has it made you reflect on your current practice?

1 2 3 4 5  Comments.................................................................

Has it given any ideas for signposting for others?

1 2 3 4 5  Comments.................................................................

What are we doing that you like? .................................................................
What could we do better? ..........................................................................................................................

If you could copy this page and email it back to janet.beasley@derbyshcft.nhs.uk
I would be really grateful to have the opportunity to see what you have thought and if
you feel that this is a worthwhile newsletter to continue.

If you would like to write, or add an article, reflection, or have a subject that you would like
to explore in number 3, then please feel free to contact us.
Hope that you have enjoyed reading Special News 2. Now once again I would be really be grateful if you could email me back your thoughts on the feedback form.

Have you got something to write about? Whether you are a child, parent, carer, a family, student, charity, association or other professionals we would be very keen for you to share your thoughts. The closing date for articles to be submitted for ‘Special News 3’ is April 10th 2016 please feel free to contact. I am base at Cardinal Square 01332 888080 ext. 88337 Janet Beasley Operational Senior Nurse janet.beasley@derbyshcft.nhs.uk