



Education Newsletter

June 2024



Happy Anniversary!

This month marks one whole year of the Education Newsletter with 12 editions sharing the latest education news and training. Thank you to everyone who has contributed to the newsletter so far! As always, if you have any ideas or something to share, please email us at clinical.education@derianhouse.co.uk

Education
at Derian House

New Starters

Alice, Heather and Dorota have been settling into their new roles as care support workers and have started their supernumerary shadow shifts with their buddies. They will soon start to work towards completing their clinical competencies.

We welcome new care support workers Sam and Emma M started their induction on the 27th May. Nurses Emma H and Leigh will join us on the 10th June.

Welcome Bridget to the team as our new Deputy Clinical Lead



Photo of our new care support workers during their BLS training in the skills lab. Left to right- Heather, Alice and Dorota

Elearning and competencies

We have sent out education compliance emails to members of the clinical care team (Nurses, AP's, NA's and CSW's) and in recognition for the large amount of clinical competencies to complete; we are rewarding 100% compliance with an entry into a draw to win a prize. We will be doing this monthly and those who are fully up to date with their competencies are entered into the draw each month.

We will soon be releasing new training on Nasogastric Tube management which will be a presentation, assessment, competency and simulation skills workshops for all clinical staff.

Some staff will be attending Parental Nutrition training in June which will help us to support and care for our cyps who



Students

We will have some fresh new students starting their placements soon. Martina is a LD Nursing student joining us from UCLan and Hayley is a midwifery student also from UCLan, Victoria is a Health Visitor joining us for her return to practice placement through Plymouth University. Haleema and Rebecca will still be on placement with us throughout June.

Please can all nurses self declare as an assessor or supervisor on PARE

The next **Student Supervisor and Assessor Update training is on MTeams on the 16th July 6pm-8:30pm**. Please check your emails for the link



Care of the child with cancer course

Faye and Charlotte attended a two-day care of the child with Cancer course at Royal Manchester Children's Hospital on the 1st and 2nd May. Here are some reflections from Charlotte about what she has learned...

"I have learned about the amount of services offered from the point of diagnosis and how CYP'S are supported through the RMCH pathway including all the various treatment options that the CYP could be offered. I learned all about gene therapy, about how it is only licensed for certain types of cancer, usually ALL (Acute Lymphoblastic Leukaemia), and how there are only 3 centres that provide gene therapy".

I increased my understanding of immunotherapy, how there is a criteria eligibility to get onto the Car T Cell therapy and how the patients once commenced the transfusion and how they monitor any of the side effects.

Bone Marrow Specialist Nurses - the differences between autologous transplant and allogenic transplant and then following the journey of how the Bone Marrow takes place. Fun Fact - If a person has a bone marrow transplant it can change the person's blood type and DNA!



Charlotte, Nurse Associate



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A reflection on Training: Josie, Trainee Nurse Associate



I am now around 3 months into my Trainee Nurse Associate Course. I'm really enjoying it so far. I attend UNI on a Friday where the course is split into theory sessions and practical sessions. I have a learning journal of any new knowledge or skills I have gained here at Derian since starting the course, so if anybody is doing anything interesting that I might not have seen before, please let me know if I can come along! I am going on my first external placement week commencing 3rd June with ex-Derian nurse Jenny B who manages a team of health visitors around the Blackpool area. I'm really looking forward to getting a mixture of external placements covering adult nursing, mental health and other types of child nursing.

Professionals Day and Student Day

Our next professional's day will be held on 18th June in the conference room. This is where health and social care professionals visit us and learn about what we do here at Derian House, partake in workshops and have a tour.

The next student day will be held on 28th June and is similar, but an opportunity for student nurses and health professionals to learn more about children's hospice and paediatric palliative care. We will email about guest speakers soon and always appreciate your help!

Professional Days at Derian House

Welcome to
derian house
children's hospice



Next Dates:
Tuesday 18th June 2024
Friday 27th September 2024
Friday 22nd November 2024
2025 dates TBC

Sign up here



- About Derian House
- Meet specialised teams
- Find out about services

Awareness days in June

1st June- World Children's Day

UNICEF's annual day of action for children marking the adoption of the Convention on the rights of the child, raising awareness of children's human rights and helping children to raise their voice on issues that matter to them.



For every child, peace

Every child, everywhere, has a right to live in a peaceful world.



For every child, a livable planet

Children have a right to a safe and livable planet.



For every child, a voice

Children must be listened to and included in all decisions that affect them.

1st-30th June- Pride Month

Pride month is a vibrant and inclusive celebration that honours the LGBTQ+ community, their history, achievements and ongoing struggle for equality. Keep an eye out for pride month celebrations at Derian House.

9th-15th June- Diabetes awareness week

Diabetes UK is a charity creating awareness of the condition and experiences of people living with diabetes. Diabetes afflicts more people in the UK than other serious health condition. There are 4.6 million type 1 sufferers and an estimated 12.3 million people are potential type 2 diabetics.





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Condition of the Month: Batten Disease

What is Batten disease?

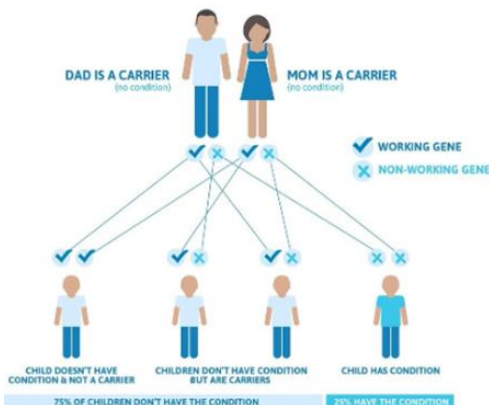
Batten disease is a group of rare, progressive neurodegenerative, genetic metabolic diseases. It is a rare and terminal neurodegenerative condition, also known as neuronal ceroid lipofuscinoses. How *CLN* mutations lead to Batten disease isn't fully known, but they are thought to interfere with cells' ability to break down and recycle their waste products. This function is performed by lysosomes, which act as the cell's "trash cans," and Batten disease is therefore classified as a lysosomal storage disorder. The cells try to compensate by making more lysosomes, which get larger and larger and eventually release their contents into the cell. The cells eventually get overwhelmed and die. Cells in the nervous system seem to be especially vulnerable

Diagnosis

There are 13 known forms of Battens disease, divided into five main categories: congenital, infantile, late infantile, juvenile, and adult Batten disease.

Children may appear healthy and develop normally for the first few years of life before they begin to show symptoms. A child may develop seizure of vision loss, their development may slow or stop and they begin to display other symptoms including lack of concentration, loss of language and loss of motor skills.

Autosomal Recessive Inheritance Pattern



Gene	Disease Name	Also Known As
CLN1	CLN1 disease, infantile CLN1 disease, late infantile CLN1 disease, juvenile CLN1 disease, adult	Infantile
CLN2	CLN2 disease, late infantile CLN2 disease, juvenile	Late-Infantile
CLN3	CLN3 disease	Juvenile
CLN4/DNAJC5	CLN4 disease	Adult autosomal dominant Batten Kuf's disease Ceroid Lipofuscinosis Parry type
CLN5	CLN5 disease, late infantile CLN5 disease, juvenile CLN5 disease, adult	Finnish variant late-infantile
CLN6	CLN6 disease, late infantile CLN6 disease, juvenile CLN6 disease, adult	Early juvenile variant or late-infantile variant
CLN7	CLN7 disease, late infantile	Late-infantile variant
CLN8	CLN8 disease, late infantile	Late-infantile variant EPMR (progressive epilepsy with mental retardation)
CLN10/CTSD	CLN10 disease, congenital CLN10 disease, late infantile CLN10 disease, juvenile CLN10 disease, adult	Congenital classic Late-infantile Adult
CLN11/GRN	CLN11 disease, adult	Adult (heterozygous mutations cause frontotemporal lobar dementia)
CLN12/ATP13A2	CLN12 disease, juvenile	CLN12 disease Juvenile (mutations also cause Kufor-Rakeb syndrome)
CLN13	CLN13 disease, adult	Adult Kufs type B
CLN14/KCTD7	CLN14 disease, infantile	CLN14 disease, infantile

Who is affected?

Because the disease is recessive, children must have two copies of a *CLN* mutation — one from each parent — to be affected. Siblings of affected children have a one in four chance of also developing the disease, and a 50 percent chance of being a carrier.

Treatment

There is current research into gene therapy and enzyme replacement therapy in the hope of slowing down the disease progression, however, existing management includes helping to control the symptoms of Batten disease and improve children's quality of life — such as anti-seizure drugs, treatments for spasticity, medications for anxiety and other behavioural symptoms, and physical and occupational therapy. These treatments cannot cure Batten disease but can help children retain their abilities for as long as possible.

References

Batten Disease Family Association - <http://www.bdfa-uk.org.uk/about-batten-disease/>



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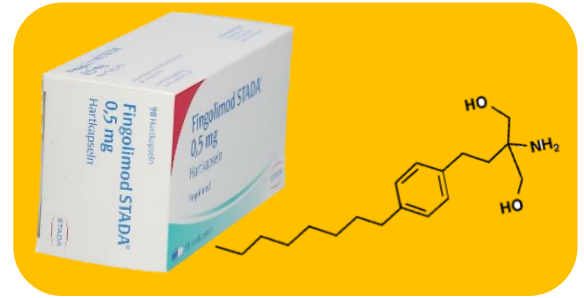
MEDICINE of the month



Why is it used?

Fingolimod is a sphingosine-1-phosphate receptor modulator, which prevents movement of lymphocytes out of lymph nodes, thereby limiting inflammation in the central nervous system. It is most commonly used for patients with multiple sclerosis, although it is being used for children and young people with Batten's disease.

Fingolimod



Dosage

Side Effects:

Common or very common - Alopecia; arthralgia; asthenia; atrioventricular block; back pain; bradycardia; cough; decreased leucocytes; depression; diarrhoea; dizziness; dyspnoea; headaches; hypertension; increased risk of infection; myalgia; neoplasms; skin reactions; vision blurred; weight decreased.

Multiple Sclerosis (initiated by a specialist):
By mouth (BNFC)

Child 10–17 years (body-weight up to 40 kg);
250 micrograms once daily.

Child 10–17 years (body-weight 40 kg and above); 500 micrograms once daily.

Cautions:

Body-weight less than 40 kg children should be brought up-to-date with current immunisation schedule before starting treatment; children under 12 years chronic obstructive pulmonary disease; history of myocardial infarction; history of symptomatic bradycardia or recurrent syncope; patients receiving anti-arrhythmic or heart-rate lowering drugs, including beta-blockers and heart rate-lowering calcium-channel blockers.

Contraindications:

Active malignancies; baseline QTc interval 500 milliseconds or greater; cerebrovascular disease (including transient ischaemic attack) in the previous 6 months; decompensated heart failure (requiring inpatient treatment) in the previous 6 months; increased risk for opportunistic infections (including immunosuppression); myocardial infarction in the previous 6 months

Interactions:

Both Atenolol and Fingolimod can increase the risk of bradycardia; Fingolimod might increase the risk of QT-prolongation when given with Citalopram. Manufacturer advises avoid.

References

BNFC (2024) retrieved from: <https://bnfc.nice.org.uk/drugs/fingolimod>