

## NEWS: 2018 MSN CYPC Education Day

The 2018 MSN CYPC Education Day (23 March, Edinburgh) was a success with a variety of speakers presenting insightful talks on the theme of 'Early Diagnosis'. Guest speaker Dr. David Walker, Professor of Paediatric Oncology at the University of Nottingham and Co-Director of [Children's Brain Tumour Research Centre](#), has been involved in the development of many campaigns, groups, guidance and research. Dr Walker presented an excellent talk on accelerating diagnosis and minimising brain injury in childhood brain tumours.



 Dr. Emma Barron, surgical trainee of the Western General, Edinburgh, presented a powerful talk on her personal experiences as a parent of a young child diagnosed with a brain tumour. Dr Barron is passionate about early diagnosis and highlighted some of the factors that impede a timely diagnosis. Dr. Barron co-founded the [Glow Gold](#) campaign.

A second compelling account of personal experiences of cancer was presented by Dr. Bob Grant. Dr Grant has worked in both Primary and Secondary Care, contributing to many groups and charities including the review of [Scottish Cancer Referral Guidelines](#). Dr Grant's own experience of a delay in cancer diagnosis has given him personal insight which has been invaluable in his work as a GP, reviewer of guidelines and with the 3rd sector.



 Dr. Nick Heaney, Haematologist and network TYA Lead, is based at the Beatson West of Scotland Cancer Centre and the Royal Hospital for Children in Glasgow. Dr. Heaney presented selected cases that highlighted diagnostic delays despite patients presenting at Primary Care and/or A & E on multiple occasions. Communication between the patient, primary and secondary care, was highlighted as the key to earlier diagnosis.

Dr. Isabel Anderson, Principal Clinical Psychologist and network Lead for Psychosocial Healthcare, is based at the Royal Hospital for Children, Glasgow. Isabel outlined the importance of recognising the psychosocial needs of children and young people early on in their care after diagnosis, and emphasised the value of the Holistic Needs Assessment in identifying distress.



All presentations from the day are available in the Healthcare Professionals area on the website [www.youngcancer.scot.nhs.uk](http://www.youngcancer.scot.nhs.uk).

3 workshops took place in the afternoon session. The day concluded with a plenary session recounting the outcomes from the day's discussions. The **TYA workshop** looked at the possible reasons for delays in diagnosis and the importance of early diagnosis with reference to cases. The **Psycho-social Healthcare** workshop examined assessment and intervention for psychosocial needs, highlighting the value of Holistic Needs Assessments. The **Primary Care** workshop looked at the role Primary Care plays with regard to referrals to Secondary Care. Communication between PC and SC was identified as a major factor in early referral. End of Treatment Summaries were identified as an effective tool for GPs regarding follow-up care.

## SPOTLIGHT - LOGAN'S FUND

### *Doing special things for children and their families affected by childhood cancer*

Logan's Fund are a children's cancer charity based in Moray who can offer support throughout Scotland to any child until they turn 18 but will consider 18+ if their diagnosis/treatment took place prior to that birthday. They will support any child in treatment, post treatment and bereaved families.



Their philosophy is to try and win back some of the childhood lost to time in hospital and give cause for optimism or an alternative focus away from hospital and beyond the treatment they are going through, for any child and their family affected by cancer.

In 2016 Logan's Fund opened [Logan's Sunny Days](#), their respite holiday caravan situated in the heart of the community where the charity is based and looking out onto the beautiful Moray Firth.



It has proved to be a real haven for families to have special relaxing holiday time together. The charity will also organise activities for families for their stay based on what they are interested in doing. Everything from surfing to climbing wall lessons to ice skating tutorials and activity park visits can be arranged as well as a tour of the local lighthouse and lots, lots more.

Logan's Fund launched their child sponsorship program **Always a Rainbow** in August 2017. This is open to any child in treatment or post treatment and also siblings of, as well as mum and/or dad where appropriate. The program is all about learning, development, gaining confidence, new experiences, having fun and meeting new friends. So far they run a weekly swimming lesson class at a local hydrotherapy pool and are just in process of starting similar lessons in Aberdeen and Edinburgh. Indoor surfboard lessons are proving popular with one eye on moving this outdoors in the summer. They also have a bereaved sibling attending a performing arts school and who recently had a starring role on stage in the school's annual Christmas production. Organisations and clubs offering everything from martial arts to ice skating to cheerleading are on board but it is really the children who will drive and grow Always a Rainbow with the things they wish to do. The sky really is the limit with Always a Rainbow as they have a teenage boy looking at starting glider lessons in the spring.

*'Seeing Sarah who has an inoperable brain tumour doing the butterfly or 10 year old Joe who is in a pool again for the first time in over 3 years is just amazing to witness', Logan's Fund chairman Cameron Mackintosh who added that 'the idea behind Always a Rainbow is to roll the program out throughout Scotland with the children and teenagers who participate dictating what the activities and pastimes are that make up the program. Its really just a massive jigsaw puzzle that we only have some of the pieces for'.*

The charity have also recently started providing specialist dry-suits in partnership with Hammond Drysuits allowing children with a Hickman line the chance to enjoy swimming pools and the beach.



To find out more, book a week at [Logan's Sunny Days](#) or contact [www.logansfund.org](http://www.logansfund.org).

## MSN CYPC UPCOMING EVENTS

The **2018 Neuro-oncology Study Day** is taking place on Friday 14th September at the COSLA Conference Centre, Edinburgh. The theme for this year's event is '**Low Grade Glioma**' and the programme will be available shortly on the MSN CYPC website. Early registration is advised - please use our [online booking facility](#). The Study Day is open to NHS staff who work with or have an interest in working with young people who have had a diagnosis of cancer. Check out Jake's animations on [The Brain Tumour Charity website](#).



## CURRENT DEVELOPMENTS WITHIN MSN CYPC WORKSTREAMS

**Aftercare:** A study day is being planned to develop standards for both paediatric and TYA age ranges. The team are reviewing the roles of Aftercare nurses and national requirement to develop a business case for future-proofing the service.

**Allied Health Professionals:** A questionnaire has been developed to scope the needs of children and young people once treatment has finished. Work is also underway in developing a sarcoma and Chemotherapy induced peripheral neuropathy pathway.

**Neuro-oncology:** The theme for this year's Imaging Study is Low Grade Glioma; this will take place in September. A national Standardised Paediatric Brain Tumour Imaging Protocol has been developed and has been circulated to all boards. Two sub-groups have been established to develop standards for neuropathology and neuropsychology.

**Nursing:** There has been excellent feedback from parents regarding the new video [Admission to hospital](#) and the photo books in 6 centres. Work is ongoing on an information video for community professionals both in shared care and the wider community and there is a possibility of a further video on Radiotherapy. Sexual Health leaflets are ready to print.

**Palliative Care:** Just In Case Box Guideline to be disseminated (Sept 2018) and reviewed after 6 months. The group along with the TYA group are to identify where services needed the most and where there are any gaps in service provision. An exercise to identify bereavement care services is underway.

**Pharmacy:** Tumour Lysis protocol completed; development of several national guidelines in progress. The first draft of a training programme for pharmacists working in CYP cancer care due shortly. Collegiate working with CCLG, NCRN and CTSIG. To review each Board's Medicines Governance with regard to the roll out of the Just In Case Box guidelines.

**Psychological Health:** A review of national and international guidelines in progress. Leaflet for parents of younger children drafted. Review of HNA and carried out workshop on HNA at Education day. Progressing with engagement with local centres.

**Teenagers & Young Adults:** Implementation and audit of the Scotland TYA Standards of care through the National TYA MDT will enable benchmarking of TYA care across Scotland. More focus on trial availability for common tumour types that affect TYA patients will be discussed at the CAG. Review of existing TYA cancer services and overview of challenges in implementing TYA model of care completed. Members of the National Youth Advisory Forum delivered an excellent presentation on raising awareness of cancer in young people through education in schools which was very well received by MSP's and others attending a recent reception at the Scottish Parliament.



Admission to Hospital video available at  
[www.youngcancer.scot.nhs.uk](http://www.youngcancer.scot.nhs.uk)

## EVENTS & CONFERENCES 2018 - [See our External Events Webpage](#)



[Genomic Medicine 2018 Edinburgh Conference](#) Edinburgh,  
18 - 19 April

[Cancer Research UK Brain Tumour Conference 2018](#)  
London, 1 - 3 May

[Foundation Oncology Skills for Nurses](#) London, 3 - 4 May

[Paediatric Solid Tumour Study Day](#) London, 4 June

[CCLG UK Childhood Cancer Conference](#) Manchester, 22  
June

[Cancer and Metabolism 2018](#) Cambridge, 25 - 27 June

[25th Biennial Congress of the European Association for](#)

[Cancer Research](#) Amsterdam, 30 June - 03 July

[Beatson International Conference](#) Glasgow, 01 - 04 July

[The 98th Annual Meeting of the British Association of Dermatologists](#) Edinburgh, 03 - 15 July

[Children with cancer - International Scientific and Medical Conference](#) London, 12 - 14 September

[36th World Cancer Conference](#) Zurich, 11 - 13 October

[Children with cancer - International Scientific and medical conference](#) London, 12 - 14 September

More dates and information on the [External Events](#) page of the website.

## ONLINE TRAINING COURSE - CHEMOTHERAPY NURSE TRAINING

All oncology nursing staff in the UK who administer **Systemic Anticancer Treatments (SACT)** are required to complete a university accredited SACT module. Newcastle University provides an online course that has been designed for registered nurses who are involved with the care of cancer patients.

The course is a 10 credit continuing professional development (CPD) module that is delivered online for 16 weeks. Fees £435. [Course requirements](#) and [How to apply](#) information.

For further information about this course please contact Newcastle University by using the [Oncology and Palliative Care form](#).

[www.youngcancer.scot.nhs.uk](http://www.youngcancer.scot.nhs.uk)

[Blog](#) for patients, parents, carers and staff. [Video Gallery](#) for patients and parents.

Get in touch if you would like to contribute to the next newsletter. Contact: [sritchie3@nhs.net](mailto:sritchie3@nhs.net).

