Although there were no significant differences in mortality between OP and controls, OP mortality was high at 25.0% compared to 8.3%. However, the deaths among the OP cohort were not directly related to OP itself. Patients with OP had higher risk of having moderate to severe intraventricular haemorrhage (IVH grades 2–3 by Volpe classification) OR 5.00 ($p < 0.05$) and combined moderate-severe IVH with mortality, OR 5.86, $p < 0.01$.

Conclusions OP is a rare complication among smaller VLBW infants. There was a high incidence of mortality of 25.0%, air leak syndrome and moderate to severe IVH.

British Association for Community Child Health

345 THE SEND STAY AND PLAY SUMMER INITIATIVE 2020

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Background On March 11th, 2020, the World Health Organisation confirmed the coronavirus characterisation (SARS-CoV-2) as a pandemic, leading to the UK being plunged into a national lockdown. This changed a nation's lives and introduced never-before-seen challenges for children, specifically those with special educational needs and disabilities (SEND), their parents and their carers.

Children, parents and carers were struggling to cope in the lockdown. In June 2020, a Parent Forum survey showed that parents and carers, living in Lambeth UK, who did not receive social care short breaks wanted to access safe, outdoor play opportunities for their children with special educational needs and disabilities.

Through discussion with Lambeth parent representatives at the SEND Strategic Joint commissioning and Engagement Board, the following recommendations were made:

- Further stay and play opportunities
- Linking up medical students to provide extra volunteer support

In June 2020, Lambeth Children with Disabilities and Integrated Children's Commissioning launched a pilot short breaks 'stay and play' scheme with three SEND and youth and play adventure playgrounds

Objectives The objective of the SEND 'stay and play' scheme, was to provide safe outdoor play opportunities for children with SEND.

Abstract 345 Table 1 Specific data per site

Site Name	Total Bookings	Total Attendees	Total Volunteers
BOST	56	89	1
Grove	65	57	2
High Trees	4	4	0
Lollard	n/a	n/a	1
Triangle	n/a	n/a	3
Kinetika Bloco	n/a	n/a	1
TOTAL	125	150	6

Methods The Lambeth SEN Inclusion Fund allocated dedicated funding for one household at a time to attend the 'stay and play' sites. A successful pilot scheme resulted in seven site providers signing up to the scheme.

Lambeth's Designated Medical Officer worked with King's College London Paediatric Society, to provide medical student volunteers:

- 24 volunteers signed up to the scheme
- 6 assisted the scheme over the three-month scheme period.

Results In total, across three sites for which data was available, 125 bookings were made, and 150 children, parents and carers attended (table 1).

Feedback from parents:

Feedback from parents was overwhelmingly positive; both they and their children appreciated the scheme's usefulness and supported its continuation. See examples below:

'Keep it open because there are no places like this around.'

'Fun and accepting of Special Needs, Very Safe Play.'

'My son loves the scheme place. We would love him to keep coming here if this place carries on.'

'Our volunteer was our shining light!'

Challenges and lessons learnt:

Although the objective was met, areas of improvement were identified. The scheme would benefit with more planning time, enabling safer volunteer recruitment, including inductions and necessary safeguarding training. We suggest six weeks in advance.

Conclusions In summary, Lambeth Children with Disabilities and Integrated Children's Commissioning Group, with the help of KCL Paediatric Society, successfully launched a 'stay and play' scheme for children with special educational needs and disabilities during the nationwide lockdown. The scheme provided a safe space for carers, parents and children, reducing the challenges posed during the ongoing pandemic; improving their mental and physical wellbeing.

Children's Cancer and Leukaemia Group

348 ALPHA-FETOPROTEIN IN CHILDREN AND YOUNG PEOPLE WITH ATAXIA-TELANGIECTASIA

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Background Patients with Ataxia-Telangiectasia (A-T) are particularly prone to develop different malignancies. Alpha-fetoprotein (AFP) is a useful tumour marker and is well-known to be raised in A-T.

Objectives We undertook a systematic review of studies reporting AFP in A-T patients and conducted a retrospective review of AFP levels in children and young people attending the

national A-T clinic in Nottingham. Here we present the results of the observational study of AFP levels.

Methods Patients' paper and electronic clinical records were reviewed from 2006–2019 and data extracted. AFP levels of A-T patients who had a malignancy were compared with those who did not have any malignancy.

Results Data were available for 77 patients age: 0.9 to 17.2 years; 38 (49.4%) females]. Six (7.8%) had a malignancy. AFP measurements (n=215) ranged from 4 to 1107 kU/L (normal range 0–10 kU/L). Mean AFP in those with a malignancy was 329.9 kU/L (range 6–541; SD 197.6) which was significantly higher than in those without malignancy at 228.8 kU/L (range 4–1107; SD 191.9, $p = 0.014$).

Conclusions The AFP levels were significantly higher in those with a malignancy than in those without malignancy. However, 70/71 children without malignancy had AFP levels in the tumour marker range. Time trend analysis is required to investigate if serial AFP measurements might be an early indicator of malignancy in A-T.

British Association for Paediatric Nephrology

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HEALTH-RELATED QUALITY OF LIFE IN CHILDREN WITH NEPHROTIC SYNDROME: A PRELIMINARY REPORT

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Background Nephrotic Syndrome (NS) is the commonest chronic glomerular disease of childhood. A majority (70–80%) have relapsing disease persisting throughout childhood. Any chronic childhood disease causes psychosocial impact and behavioural difficulties that have implications for the mental health, social and personality development of the child.

Objectives To assess the quality of life (QOL) in children with NS compared to a matched healthy control group.

Methods A case-control study was conducted in the nephrology clinic, Lady Ridgeway Hospital for Children, Colombo to assess the quality of life (QOL) in children with NS compared to a matched healthy control group. A self-administered multi-dimensional questionnaire of Paediatric Quality of Life Inventory 4 (PedsQLTM) was used to collect data. The tool evaluates the QOL in four domains: physical, emotional, social and school functioning, with higher PedsQL scores indicating a better QOL. Descriptive and analytical statistics were performed to compare scores. Possible predictors of poor outcome among the cases were assessed by both univariate and multivariate analysis.

Results A total of 51 cases and 23 controls aged 5–18 (9.96 ± 3.41 year and $6-13$ (9.2 ± 2.34) years, respectively, were included in the analysis. The mean PedsQL 4.0 Generic Core Scale score was found to be lower in cases compared to healthy controls. (78.94 vs 88.8) but there was no significant difference ($p=0.176$). There was a significantly lower score in the physical domain (79.65 vs 93.97 , $p = 0.02$, $p<0.05$). However, emotional (77.65 vs 83.82), social (82.20 vs 89.00) and school (68.43 vs 86.11) functioning were not significantly

different between cases and controls ($p > 0.05$). Children with hypertension had significantly lower mean PedsQL score compared to children without hypertension (71.6 vs 82.14 , $p = 0.04$, $p<0.05$). There were significantly lower scores in physical (65.14 vs 85.93 , $p=0.01$, $p<0.05$) and social (77.19 vs 84.56 , $p = 0.04$, $p<0.05$) domains.

Conclusions The mean PedsQL scores in all domains were lower in children with nephrotic syndrome with a significant difference in the physical domain. Hypertension was an independent risk factor associated with lower quality of life.

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HEALTH-RELATED QUALITY OF LIFE IN CHILDREN WITH BLADDER DYSFUNCTION: A PRELIMINARY REPORT

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Background Bladder dysfunction (BD) is a chronic nephro-urological condition, resulted from a multitude of aetiologies including posterior urethral valve (PUV), myelomeningocele (MMC), spina bifida, sacral agenesis and non-neurogenic neurogenic bladder. Any chronic childhood disease could trigger physical, emotional, social dysfunction and could also affect the educational performances leading to far-reaching consequences.

Objectives To assess the quality of life (QOL) in children with BD compared to age and sex-matched healthy control group.

Methods A case-control study was conducted in the nephrology and surgical clinics, Lady Ridgeway Hospital for Children Colombo. A validated self-administered multi-dimensional questionnaire of Paediatric Quality of Life Inventory 4 (PedsQLTM) was used to collect data. The tool evaluates the QOL in four domains: physical, emotional, social and school functioning, with higher PedsQL scores indicating a better QOL. Descriptive and analytical statistics were performed to compare scores. Possible predictors of poor outcome among the cases were assessed by both univariate and multivariate analysis.

Results A total of 17 cases and 26 controls aged 5–14 (9.11 ± 3.21) years and 5–13 (8.73 ± 2.58) years, respectively, were included in the analysis. The cases comprised of 13 patients with posterior urethral valves (PUV), two patients with meningomyelocele and one patient each of spina bifida and sacral agenesis. The mean PedsQL 4.0 Generic Core Scale score was found to be lower in cases compared to healthy controls (71.33 vs 82.62) but there was no significant difference ($p=0.076$). There was a significantly lower score in the physical domain (71.39 vs 84.80 , $p=0.028$). However, emotional (74.53 vs 79.00), social (74.00 vs 86.50) and school (66.80 vs 79.50) functioning were although lower, not significantly different between cases and controls ($p > 0.05$).

Conclusions The mean PedsQL scores in all domains were lower in children with bladder dysfunction with a significant difference in the physical domain.