



# Roald Dahl Specialist Nurses' Conference 2021

14 – 15 October 2021

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MULTIMEDIA **PLUS**

30 years of providing specialist nurses  
and support for seriously ill children

# Marvellous Milestones

2021 marks 30 years since the charity was founded by Roald Dahl's Widow, Felicity Dahl.

We kicked off our anniversary year by reflecting on some of our Marvellous Milestones from the last 30 years.

<p>We currently support over <b>21,000 children</b> But we know there are over <b>100,000 children</b> with complex, lifelong illnesses. It is our ambition to provide specialist nurses and support for <b>every</b> seriously ill child.</p>		<p><b>1991</b> Felicity Dahl, Roald Dahl's widow establishes Roald Dahl's Marvellous Children's Charity</p>		<p><b>1992</b> The charity creates the first-ever Paediatric Epilepsy Specialist Nurse Post in the UK</p>	
<p><b>2001</b> The charity establishes the first Roald Dahl Sickie Cell Specialist Nurse</p>	<p><b>2001</b> The 25th Roald Dahl Specialist Nurse is established at the University Hospital of Wales</p>		<p><b>1999</b> The first Roald Dahl Specialist Nurse in Wales is appointed</p>	<p><b>1997</b> The 10th Roald Dahl Specialist Nurse is appointed</p>	<p><b>1995</b> The first Roald Dahl Specialist Nurse in Scotland is established</p>
<p><b>2004</b> The first Roald Dahl Nursing Conference took place</p>	<p><b>2009</b> Roald Dahl Haematology Specialist Nurse Phil Daly is featured on the cover of 'Nursing Standard'</p>	<p><b>2014</b> Felicity Dahl, on retiring as Trustee of the Charity, becomes its Co-President with Sir Quentin Blake</p>	<p><b>2014</b> The 50th Roald Dahl Specialist Nurse is appointed</p>		<p><b>2014</b> The Marvellous Nurse Inventing Room is launched in partnership with the Burdett Trust for Nursing</p>
<p><b>2016</b> To celebrate 100 years since the birth of Roald Dahl the new Roald Dahl rose created by David Austin Roses</p>		<p><b>2016</b> The charity creates the first-ever SWAN (Syndromes Without a Name) Nurse Specialist Post in the UK</p>		<p><b>2016</b> The charity creates the first-ever Rare Disease Specialist Nurse posts in the UK</p>	<p><b>2014</b> The charity creates the first Roald Dahl Neuromuscular Specialist Nurse Post</p>
<p><b>2017</b> The first Roald Dahl Neurodisability Specialist Nurse in Northern Ireland is established</p>		<p><b>2017</b> The first Roald Dahl Play Specialist Post is created at University College London Hospital</p>	<p><b>2017</b> HRH The Duchess of Cornwall officially became our Royal Patron</p> <p><small>Photo credit: Ian Turner</small></p>		<p><b>2018</b> Our 70th Roald Dahl Specialist Nurse Katrina Bottle started in post</p>
<p><b>2020</b> Sir Quentin Blake creates special illustration to be auctioned off for the charity's Roald Dahl nurses appeal</p>	<p><b>2020</b> Roald Dahl Transition Specialist Nurse, Giselle Padmore-Payne wins the RCNi Child Health Award</p>	<p><b>2019</b> Roald Dahl Haematology Specialist Nurse, Elizabeth Joshua-John wins Nursing and Midwifery Zenith Global Health Award</p>		<p><b>2019</b> The charity creates the first Gastroenterology Specialist Nurse Post</p>	
<p><b>2020</b> Roald Dahl Nurses are featured on the iconic Piccadilly Lights billboard</p>		<p><b>2020</b> 20 Roald Dahl Nurses are selected for the Florence Nightingale Foundation Leadership Programme</p>	<p><b>2021</b> The 80th Roald Dahl Specialist Nurse is appointed in the charity's 30th anniversary year!</p>		<p>Making Lives More Marvellous Since <b>1991</b></p>

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Illustrations © Quentin Blake

# Foreword from Licky Dahl

When I started the charity 30 years ago, I never dreamed that today I would be greeting a network of over eighty specialist nurses across the UK, all of whom bear Roald's name. I am so proud of you all. It's a source of great satisfaction and joy to me – and to my Co-President, Sir Quentin Blake – to know that all of you out there are providing essential support and care for children and their families across the UK.



There are many landmarks I can recall on this journey. But let me mention just two of them: the creation of the very first specialist epilepsy nurse in the UK and the first SWAN Nurse for children without a medical diagnosis. Both were wonderful examples of our support for innovation within under-resourced areas of children's healthcare.

My mother was a nurse and I grew up around Birmingham. So, when I visit the Birmingham Women and Children's Hospital, it's lovely to know that the charity helped establish the amazing Rare Diseases Unit there. Quentin's glorious stained-glass windows, filled with all of Roald's characters, have helped put a smile on the face of many children who are treated there. I know all you wonderful nurses do that every day.

It is my hope that in bringing you all together, this conference will be a time of reflection and inspiration. There's much to whet the nursing appetite. On the first day, Professor Sally Shearer shares her thoughts on the value of specialist nursing, while on Day 2, Michelle Johnson, Gemma Stacey, and Dr Marie Marshall will discuss nurse leadership. The power of partnerships and nurse-led innovation will be highlighted throughout the conference.

I would like to say a huge thank you to all Roald Dahl Specialist Nurses for your tireless efforts – particularly during the recent Covid-19 pandemic. I am humbled by what you do and wish we could all be together so I could thank you in person.

I continue to believe that Roald Dahl's Marvellous Children's Charity has an important role to play, supporting under-resourced areas of our NHS. We have only just started. One day I hope every seriously ill child has the support of a Roald Dahl Specialist Nurse. But in the meantime, thanks to all your efforts, I feel confident that, after its first thirty years, Roald Dahl's Marvellous Children's Charity has certainly lived up to its name.

A handwritten signature of Licky Dahl in black ink, written in a cursive style.



# About the conference

Over the past 30 years, Roald Dahl's Marvellous Children's Charity has partnered with the NHS to embed specialist nurses within the Service. Roald Dahl Specialist Nurses are instrumental in providing integrated care to more than 24,000 children and young people with complex and life-long conditions, supporting them and their families across primary, secondary, and tertiary care, social care, education and community care.

Our conference brings together Roald Dahl Specialist Nurses to learn from each other, and sector experts to ensure that they meet their goals of improving healthcare quality standards, patient safety and experience of care for seriously ill children and young people. Also invited are NHS organisations, sector leaders and key stakeholders to reflect on the importance of listening to patients and the value of specialist nursing.

**We have just appointed  
our 82<sup>nd</sup>  
Roald Dahl Specialist Nurse**



Over the past 18 months, the pandemic has hit our population of seriously ill children and young people hard, particularly those transitioning between children's and adult services. By listening to nurses, children, young people and their families, we have already been able to further refine our programmes and add in new support, such as a partnership with Citizens Advice Cardiff and Vale to establish a UK-wide financial and benefits advice service for all the families under the care of a Roald Dahl Specialist Nurse.

The whole conference is focused on the value of specialist nursing with the themes of integrated care, patient safety and nurse-led leadership and innovation. As well as your contribution, we will also include the voices of sector leaders, young people and their families as they describe their own experiences and needs, the context of specialist nursing care, the strategy of the charity, patient safety and innovation.

**Together the network has an  
incredible reach - with nurses  
employed by  
44  
NHS organisations covering  
approximately  
130  
local authority regions**

# Locations of Roald Dahl Specialist Nurses



**Roald Dahl Nurses** are specialists at providing support, information and practical care for seriously ill children and young people, working in NHS Trusts and Health Boards across the UK. They are a vital lifeline to the whole family, often supporting them emotionally as well.

Roald Dahl Nurses work with children and young people affected by complex, lifelong illnesses that are under-funded and under-resourced including epilepsy, rare diseases, Sickle Cell Anaemia, and neuro-muscular conditions. Roald Dahl Nurses also support children as they transition into adulthood. Our incredible nurses are all highly trained, senior professionals who can 'make things happen' both in the hospital and the wider community setting such as with schools or GPs. Many will have completed specialist courses in a variety of specialist areas and will be leaders within their areas of expertise. They will also be giving advice to other healthcare professionals as the areas they deal with are often complex and cross over into many other clinical specialisms.

# Agenda Day 1

## 8:45 Registration

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### 9:00 Welcome

#### Welcome & housekeeping

**Donald Sturrock**, *Roald Dahl's Biographer and Chair of Trustees, Roald Dahl's Marvellous Children's Charity*

#### Welcome message

**Julie Walters**, *Patron*

#### Welcome message

**Ruth May**, *Chief Nursing Officer for England*

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### 9:15 Where it all started

**Donald Sturrock** in conversation with **Anne Sweeney**, *the first Roald Dahl Specialist Nurse*

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### 9:30 Roald Dahl Specialist Nurse role's impact



**FILM:** *Anne Sweeney in conversation with Abbie who was one of Anne's patients for many years.*

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### 9:35 Roald Dahl's Marvellous Children's Charity strategy and plans

**Louise Griew**, *Chief Executive, Roald Dahl's Marvellous Children's Charity*



**FILM:** *Marvellous Family with Tina, their Roald Dahl Rare Disease Specialist Nurse*

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### 9.50 KEYNOTE ADDRESS

#### Why is the role of a specialist nurse so important to children with serious, lifelong illnesses

**Professor Sally Shearer OBE**, *Chair of the Association of Chief Children's Nurses, Executive Director of Nursing and Quality, Sheffield Children's NHS Foundation Trust*

Interview with **Dr Chinwe Ude**, *Paediatric Consultant (Epilepsy & Neurology) Dartford & Gravesham NHS Trust*

Followed by Q&A

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## 10:40 Break

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### 11:00 What have we learnt about transition in the last two years

**Jodi Betts**, *Lead Nurse of Paediatric Haematology and Oncology, Cambridge University Hospitals NHS Foundation Trust and Trustee, Roald Dahl's Marvellous Children's Charity*



in conversation with:

**Professor Angela Horsley MBE**, *ECHO Transition Partnership Manager, Hospice UK and former Head of Children, Young People and Transition, NHS England/Improvement*

**Dr Colin Dunkley**, *Consultant Paediatrician, Sherwood Forest Hospitals NHS Foundation Trust*

**Louise Porter**, *National Lead Nurse for Healthcare Transition of Children and Young People, Leeds Teaching Hospitals NHS Trust*

**Fiona Wylie**, *Senior Nurse for Strategy and Leadership Development, The Prince & Princess of Wales Hospice, Glasgow*

**Gerard Crofton-Martin**, *Head of Research, Practice Improvement and Co-production, Social Care Institute for Excellence*

**Virginia Tshibangu**, *Parent of a seriously ill young person, cared for by a Roald Dahl Specialist Nurse*

Followed by Q&A

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### 11:50 Reflections & Closing Address

**Donald Sturrock**, *Roald Dahl's Biographer and Chair of Trustees, Roald Dahl's Marvellous Children's Charity*

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## 12:00 Day 1 Close

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# Agenda Day 2

## 9.00 Welcome

**Louise Griew**, Chief Executive, Roald Dahl's Marvellous Children's Charity

## 9.05 KEYNOTE ADDRESS

### Importance of integrated care and listening to the patient/patient's families' voices

**Claire Hayward**, parent of seriously ill child under the care of a Roald Dahl Specialist Nurse

## 9.15 National update on mental health and wellbeing of children and young people with lifelong conditions

**Emma Wadey**, Head of Mental Health Nursing, NHS England and NHS Improvement

## 9.40 Learnings and innovation in children's services from the COVID-19 pandemic

**Kath Evans**, Director of Nursing (Children) Barts Health & the Clinical lead for Babies, Children & Young People, North East London



in conversation with:

**Bethan Williams**, Roald Dahl Specialist Transition Nurse, University Hospital Lewisham

**Dr Claire Lundy**, Consultant in Paediatric Neurodisability, Royal Belfast Hospital for Sick Children

**Dr Nighat Arif**, NHS GP

**Claire Hayward**, parent of seriously ill child under the care of a Roald Dahl Specialist Nurse

Followed by Q&A

## 10.35 Break

## 11.00 Importance of leadership and professional development for specialist nurses

### How can we further support the professional development of our Roald Dahl Specialist Nurses?

**Lisa Cutsey**, Roald Dahl Transition and Neuromuscular Specialist Nurse

**Elizabeth Joshua-John**, Roald Dahl Haematology Specialist Nurse discuss their experience of Florence Nightingale Foundation leadership programme

Followed by:

**Louise Griew**, Chief Executive, Roald Dahl's Marvellous Children's Charity



in conversation with

**Michelle Johnson MBE**, Chief Nurse and Director of Patient Experience at Whittington Health NHS Trust & Trustee, Roald Dahl's Marvellous Children's Charity

**Professor Gemma Stacey**, Director of Academy, Florence Nightingale Foundation

**Dr Marie Marshall**, Consultant Nurse for Transition, Manchester University NHS Foundation Trust

**Mark Esho**, Entrepreneur

Followed by Q&A

## 11.50 Reflections & Closing Address

**Louise Griew**, Chief Executive, Roald Dahl's Marvellous Children's Charity

## 12.00 Day 2 Close

# Speaker Biographies

## Keynote Speakers



### **Prof Sally Shearer OBE**

**Executive Director of Nursing and Quality, Sheffield Children's NHS Foundation Trust, Visiting Professor Sheffield Hallam University, Chair of the Association of Chief Children's Nurses**

Moving to Sheffield in 2016, Sally previously led children and young people's services in Nottingham and East London. In addition to her Board role, Sally's portfolio includes leading the development of an integrated children and young people's service across Sheffield and preparing the Trust for Pathway to Excellence® accreditation. Sally was awarded the Gold CNO Award in January 2020 and received an OBE in the October 2020 Queen's Birthday Honours list.



### **Claire Hayward**

**Parent of seriously ill child under the care of a Roald Dahl Specialist Nurse**

Claire is a mum first and foremost, to two exceptional boys, one of whom has very complex medical, learning and emotional needs. Claire is an NHS Occupational Therapist of 21 years, working primarily with children with complex communication needs and neurodisabilities. Having this dual perspective makes her even more passionate about the critical need to recognise and integrate parents knowledge and views, and how services must see a child's whole life picture across hospital, home, social environment and school.



### **Dr Nighat Arif**

**NHS GP**

Dr Nighat Arif is an NHS GP based in Buckinghamshire, mum to three young boys, one who has had a liver transplant. In her work, she looks after multiple families who have children with chronic illnesses as well as managing her own son. Dr Nighat specialises in women's health and family planning.

Dr Nighat is the resident doctor on BBC *Breakfast*, ITV's *This Morning* and BBC *Look East*, updating viewers on the latest medical news. She is an ambassador for multiple charitable causes such as Roald Dahl Marvellous Children's Charity, The Good Grief Trust and Sikh Forgiveness. [@drnighatarif](#)



### **Jodi Betts**

**Lead Nurse of Paediatric Haematology and Oncology, Cambridge University Hospitals NHS Foundation Trust and Trustee, previously a Roald Dahl Nurse.**

Jodi is the Lead Nurse of Paediatric Haematology and Oncology at Cambridge University Hospitals NHS Foundation Trust. She was previously a Roald Dahl Nurse.





## **Gerard Crofton-Martin**

### **Head of Research, Practice Improvement and Coproduction**

Gerard joined SCIE in 2020 and is SCIE's Programme Director for SCIE's work on both Safeguarding and on Improving National Policy and Practice. Gerard has worked on improvement & transformation programmes for over 10 years and leads SCIE's national work in this area.

Gerard has been a member of a number of advisory Boards, for example, the Health & Care Publications Advisory Board which oversaw official and national statistics publications across the sector. Gerard is currently a member of the CHKS accreditation council, advising on the development and publication of ISO accredited quality standards for health and care organisations.



## **Dr Colin Dunkley**

### **Consultant Paediatrician at Sherwood Forest Hospitals , NHS Foundation Trust**

Dr Colin Dunkley was appointed as a Consultant General Paediatrician at Sherwood Forest Hospitals in 2005. He trained in Leeds and Nottinghamshire and completed an Epilepsy Fellowship in 2004 at Great Ormond Street Hospital, London. He leads local monthly young people's epilepsy clinics.

He is the Clinical Lead for the national audit Epilepsy12 since 2009 and also works with the BPNA supporting PET content development. His career interests have centred on implementation and quality improvement strategies for children and young people with epilepsies.



## **Mark Esho**

### **Entrepreneur**

Mark Esho graduated from De Montfort University in 1994 after obtaining an MBA in Business Administration.

When Mark was five years old, he went from a happy, carefree child to becoming paralysed overnight. He had contracted the poliovirus, which by that point should have been eradicated from the UK. He was initially given a 10% chance of survival but not only did he survive – he thrived.

Mark has overcome what others might perceive as insurmountable obstacles to become the man he is today. His positive, can-do mindset has meant that not only did he finish his studies and graduate from De Montfort, but he went on to become the Founder of several successful businesses.

He now spends his time running his businesses and public speaking at events.

Mark will teach you that it doesn't matter what obstacles life throws at you – it's how you respond that counts!



## **Kath Evans**

### **Director of Children's Nursing/Chair of the Children's Board, Barts Health**

Kath is a registered general and children's nurse, her career has included clinical, educational, managerial, service improvement, commissioning and professional leadership roles.

Kath is currently Director of Children's Nursing at Barts Health, whilst also working with North East London Integrated Care System as Clinical Lead to the 0-25 Transformation Programme, as an Academic fellow at City University and a CYP Participation champion at NHS England (London).

Kath has previously worked nationally as Experience of Care Lead for Maternity, Infants, Children and Young People at NHS England. Prior to that she was at the NHS Institute for Innovation and Improvement.



## **Louise Griew**

### **Chief Executive**

Our team is led by Chief Executive Louise Griew with support and supervision from our Board of Trustees. Louise joined the charity in June 2019, having previously worked as CEO of the RAF Sports Federation, and Director of Fundraising and Communications for the Dame Kelly Holmes Trust, Greenhouse Sports and the Mayor's Fund for London. Before this she spent much of her career working in sport marketing and sponsorship agencies.



## **Professor Angela Horsley MBE**

### **ECHO Transition Partnership Manager, Hospice UK and former Head of Children, Young People and Transition, NHS England/Improvement**

The focus of Angela's working life and her passion for her chosen career is the continuous improvement of healthcare for children and young people. Within her previous national role as Head of Children, Young People and Transition, NHS Improvement, Angela provided nursing advice relating to children and young people's health care to the Chief Nursing Officer, England. In 2018 she developed an Improvement and Assessment Framework for children and young people. From 2019-2021 Angela led an England wide collaborative that aimed to improve healthcare transition for children and young people requiring physical and mental health care.

Angela has recently retired from the NHS but now works for Hospice UK as the ECHO Transition Partnership Manager. She is also a Volunteer Counsellor for Childline.



## **Michelle Johnson MBE MSc**

### **RGN/RSN Queen's Nurse, Chief Nurse, Whittington Health NHS Trust & Trustee**

Michelle has worked within the NHS in London as a registered adult and child nurse for her whole career spanning over 30 years. She has held senior operational management and nurse leadership posts in hospital, mental health and community health services across north London. Before joining Whittington Health in February 2018 as chief nurse and director of allied health professionals she worked for Barts Health NHS Trust as a corporate director of nursing for children and young people.

She is a Trustee on the Board of Directors for Roald Dahl Marvellous Children's Charity.

Michelle was awarded an MBE in the Queen's New Year's Honours 2021. Since January 2021 Michelle has taken on the Interim Chief Nurse role at Camden and Islington NHS Foundation Trust alongside her Whittington Health role.



## **Dr Claire Lundy**

### **Consultant in Paediatric Neurodisability at Royal Belfast Hospital for Sick Children**

Dr Claire Lundy is the clinical lead for the regional children's neurodisability service in Northern Ireland. Having worked in Evelina, London and King's College Hospital she has worked with an innovative multidisciplinary team in Belfast to develop a new service in Northern Ireland bringing improvements in access to tertiary treatments such as botulinum toxin and tone modifying medication.

Dr Lundy is a strong advocate for multidisciplinary working and throughout the COVID pandemic, her service was able to flex and adapt to meet the needs of children and families.



## **Dr Marie Marshall**

### **Consultant Nurse in Transition, Manchester University NHS Foundation Trust**

Marie is a Consultant Nurse for Healthcare Transition at Manchester Foundation Trust (MFT). The role is a clinical academic position in which Marie's clinical time involves working strategically across MFT to support a systems wide approach to the transition and transfer of healthcare for children and young people with long term health conditions. The clinical aspects of her role are to influence the transition work required from the ten hospitals and their specialist clinical services to ensure that there are cohesive processes and pathways in place.

Marie was awarded her PhD in 2010 and continues to develop her research portfolio, she is currently exploring the Role of the Youth Worker in the Hospital Setting and what they can offer to the care of Young People and the Clinical Teams that is different from what other professionals provide.

In 2018 Marie obtained a Florence Nightingale Emerging Leaders Fellowship.



## **Ruth May**

### **Chief Nursing Officer, England**

Ruth enjoyed national appointments with NHS Improvement and Monitor as well as regional and Trust leadership roles before becoming the CNO for England in January 2019. As Regional Chief Nurse for the Midlands and East, she championed the 'Stop the Pressure' campaign; nearly halving the number of pressure ulcers in the region, improving care for patients, and delivering cost savings to the NHS.

Ruth is passionate about nurturing the next generation of NHS nursing, midwifery and AHP leaders, encouraging professional development opportunities and putting in place the optimal cultural conditions for all NHS employees to thrive. This includes advocating for improved mental health awareness, championing volunteer activity to support the frontline workforce and she is a vocal supporter of the WRES agenda and increased diversity across the NHS.

Proud mum to her wonderful daughter, Ruth is a great believer in a healthy professional and home life balance for all. Find Ruth on twitter [@CNOEngland](#) / [#teamCNO](#)



## **Louise Porter**

### **National Transition Lead, Leeds Teaching Hospitals**

Louise is a Registered Children's Nurse who also has a degree in Business Management. Her role is National Lead Nurse for Transition with The Burdett National Transition Nursing Network.

Louise has been funded by the Burdett Trust for Nursing since 2015, initially working in a project management role, supporting all services in Leeds Teaching Hospitals Trust (LTHT) to identify best practice transition pathways for young people with a long term condition, when moving from children's in to adult services.

Owing to the success of the transition project in Leeds Louise was appointed to the role of National Lead Nurse for Transition, forming The Burdett National Transition Nursing Network in April 2019.

Louise is also Chair of The National Transition Leads Network, Deputy Chair of NHS E & I Transition Capabilities Steering Group, and a Study Advisory Group member for NCEPOD Transition study.



## **Professor Gemma Stacey**

### **Director of Academy**

Dr Gemma Stacey is a Mental Health Nurse and, prior to joining the Florence Nightingale Foundation, was employed as an Associate Professor at the University of Nottingham.

She is currently Director of the newly formed Florence Nightingale Foundation Academy where she is leading a strategy to establish the Academy as an independent 'go to' service for leadership development opportunities, identifying and exploiting evidence, and the provision of expert, well-informed opinion and advice on issues that impact on patient care and experience.



## **Donald Sturrock**

### **Chair of Trustees**

Donald is Roald Dahl's biographer and Director of Music Link International which promotes the orchestral music commissions based on Roald Dahl's children's stories. He has known the Dahl family since he made a television documentary about Roald for the BBC in 1985.



## **Anne Sweeney**

### **The first Roald Dahl Specialist Nurse**

Anne has worked in many different and varied areas of the NHS.

Anne was the first Children's Epilepsy Specialist Nurse which was supported by the Roald Dahl Foundation, taking up her post in May 1993 at Alder Hey Children's Hospital.

Anne has provided support, information and education for those with a diagnosis of epilepsy.



## **Virginia Tshibangu**

### **Sickle cell and Thalassaemia clinical nurse specialist, Kings College Hospital, London Parent of a seriously ill young person, cared for by a Roald Dahl Specialist Nurse**

Virginia is currently working as clinical nurse specialist delivering specialist Haemoglobinopathies support to adult and transition patients with sickle cell disease and thalassaemia. Her interest in sickle cell disease and transition spans 25 years (her son, who has sickle cell, is now 25 years old). Her role involves supporting patients and their parents when the young person has been transitioned to adult services, helping them to understand the difference between children and adult services and helping them navigate this very challenging period while coping with a chronic health condition.

She is keen to see transition services expanded and become an integral part of health and social care to better improve the quality of life of our young people with life limiting conditions, no matter where in the country they receive their care.



## **Dr Chinwe Ude**

### **Paediatric Consultant (Epilepsy & Neurology), Dartford & Gravesham NHS Trust**

A Paediatric Consultant with additional expertise in children's Epilepsy and Neurology whose background is in epilepsy/neurology with extensive training in Neurology at Cambridge University Hospital, Addenbrookes. An NHS consultant since 2016 and the Clinical Lead for the Paediatric Epilepsy and Neurology Service at Sherwood Forest Hospitals NHS FoundationTrust.

A proud Health Advisor and Ambassador for the Roald Dahl's Children's Charity and a volunteer for Age UK Medway.



## **Emma Wadey**

### **Head of Mental Health Nursing, NHS England and NHS Improvement**

Emma is a mental health nurse leader with 25 years of experience across a wide range of health, emergency care and criminal justice settings. Maintaining clinical practice throughout her career has always been a priority and Emma continues to work as a Consultant Nurse in a local Psychiatric liaison service based in a large acute hospital.

Emma is committed to continual professional development and advanced practice and has developed clinical academic pathways for mental health nurses and contributed to the development of competency frameworks in advanced practice. She has worked with the National Midwifery team building on the success of the Professional Midwifery Advocate program to develop a Professional Nurse Advocate program.



## **Bethan Williams**

### **Roald Dahl Specialist Transition Nurse**

A Children's Nurse who has worked in south-east London for the past eleven years. Before starting her Transition Role, she worked across most areas within the CYP Acute Pathway (Children's A+E, Assessment and Ambulatory Unit, Children's Inpatient Ward) for the NHS, as well as working as a Paediatric Site Manager within Private Healthcare.

Since taking on the Transition Role she set up a Youth Board within her Trust as she feels it is vital the voice of the Young Person is heard, especially when we are working towards improving and developing services for them.



## **Fiona Wylie**

### **Senior Nurse for Strategy and Leadership Development, The Prince & Princess of Wales Hospice, Glasgow**

Fiona Wylie works as a Senior Nurse for Strategy Implementation and Leadership Development at the Prince and Princess of Wales Hospice (PPWH), having taken up this post in 2016. Fiona's career in nursing has been varied since qualifying in 1988 including various appointments within Women's Health ending up as a Senior Charge Nurse within Gynaecology. During this time Fiona developed a passion for leadership within nursing and how this influenced the care given to patients and their families. This led to Fiona completing an RCN Leadership Programme; a Leadership and Management programme provided by The Institute of Leadership and Management (formerly NEBS) and an 18-month RCN Clinical Supervision programme. All the above supported a year's secondment to a gynaecology redesign project before completing her career in women's health.



# Thank You

On behalf of thousands of seriously ill children across the UK, we would like to thank everyone who currently makes our work possible – including our marvellous dedicated and caring team of Roald Dahl Specialist Nurses and the NHS Trusts they work for, charity staff, Royal Patron, presidents, patrons, ambassadors and volunteers.

Thanks to everyone at Multimedia Plus, especially Tess and Guy Ferguson, for producing the conference to such a high standard.

Thank you to UCB for supporting this conference through an educational grant.

Thank you to our Trustees for their support.

# Impact of Roald Dahl Specialist Nurses

Our experienced Roald Dahl Specialist Nurses are a vital lifeline for seriously ill children and young people as well as their families. They are also an invaluable asset for the NHS Trusts and Health Boards where they work, the medical teams and the community at large.

The role of Roald Dahl Specialist Nurses is unique and goes beyond traditional nursing care to cross organisational boundaries to deliver holistic care for their young patients and their families.

“ Our Roald Dahl Specialist Nurse Clare has been a godsend. I don't know what we would have done without her. ”

Parent of a seriously ill child

**Our 82 Roald Dahl Specialist Nurses are based throughout England, Wales, Scotland and Northern Ireland and support over 24,000 seriously ill children and young people living in every corner of the UK.**

**Our key strategic aim is to improve the healthcare outcomes and resilience of seriously ill children and their families living with complex, lifelong, and under-funded conditions.**



## Roald Dahl Specialist Nurses

Roald Dahl Specialist Nurses are a vital lifeline to the children and their families, supporting them clinically and emotionally. They co-ordinate care and are often there for them until adulthood. Although Roald Dahl Nurses operate across a number of different specialisms, they are all specialist nurses who are making a huge difference to children and families.



## Nurse Development

Nurse Development is key to a Roald Dahl Nurse improving the care and support they give. We work with our nurses to offer opportunities to improve their skills, to build a peer network and to ensure that best practice is shared across the Roald Dahl Nurse network. We also work with our nurses on leadership and service improvement, making them incredibly valuable to their services.



## Nurse Led Innovation

We support Roald Dahl Nurses to solve problems creatively. Using a cohort approach, and through forming partnerships we work closely with our nurses to improve healthcare outcomes for children through innovation.



## Marvellous Family Support Service

Our Marvellous Family Support Service helps families to access their benefit entitlements. This support service helps families to overcome financial worries, helping to relieve some of their stress and anxiety.

“

**[Our Roald Dahl Specialist Nurse] has been a godsend to us at some of the lowest points in my life. I honestly don't think I would mentally be where I am now without her.**

”

**Parent of a seriously ill child**



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