Success Charity 7th Annual Conference: for Survivors by Survivors

Successful Destinations

2nd March 2024 9am-5pm – 1 Wimpole Street, London

08:20 – 09:15	**ARRIVAL & REGISTRATION**			
08:40 – 09:50 Central Atrium, Cavendish and ENT Rooms and Max Rayner Foyer	**Preparing for Departure: "Destination Lounge"**			
	Meet Trustees, Learn about SUCCESS and our Support Programmes: TeleRehabilitation, Peer to Peer and Educational Programmes, Health Service Research, Social and Creative Activities and the Bravehearts Magazine Tell Your Story and Have Your Picture Taken			
	Tea, Coffee and Pastries			
09:50 – 10:00	**Pre- Introduction Notices**			
Auditorium 1	Health and Safety & How to Participate [Slido]		Doug Stewart	
10:00 - 11:30	**Plenary Session 1**	**Where Are We Going?**		**Craft Breakout**
Guy Whittle Theatre Chair: Dr Spoudeas	**The Vision for SUCCESS**	**Introduction and Welcome**		**Lower Floor Training Suite**
10:00 – 10:05	Successful Destinations: Where are we Going and How Do We Get There?		Dominic Grieve KC Patron	Elwin Harewood
10:05 – 10:15	The Road Ahead: The Journey to SUCCESS Survivorship Hubs of Excellence		Dr Helen Spoudeas Founder	
10:15 – 10:30	Evaluating the Current State of Rehabilitation: A SUCCESS Gap Analysis with Great Ormond Street Hospital		Daniel Bell Neurophysiotherapist On behalf of GOSH Survivorship Clinic	Relational Art Therapist
	The Survivors' Voice	**Our Journey, Our Words**		
10:30 – 10:45	When The Tumour is Cured and You Find Yourself Alone - Who Understands?		Laura Bailey	
10:45 – 11:00	When The Cancer Hauntingly Returns - What Care is Missing?		Youssef Ghanem	
11:00 – 11:15	When a Craniopharyngioma Proves Difficult - Are Pituitary Surgeons Accessible?		Olivia and Mrs Harding	
11:15 – 11:30	When a Tumour Produces Hormones - Are Pituitary Physicians Key to Care Across the Age Divide ?		Grace Kearns	
11:30 – 12:00	**COFFEE BREAK**			
12:00 – 13:00	**Parallel Session 2**	**Cruise Liners vs Life Rafts: Are We All in This Together?**		**Craft Breakout**
Guy Whittle 1. Max Rayner 2.	**1. Newly endorsed CCLG National Guidelines and Specialist Pituitary Tumour Services** **Chairs: Messrs Simon Cudlip and Kristian Aquilina**		**2. Specialist Health and Education Services** **Chairs: Drs Jane Williams and Peta Sharples**	**Lower Floor Training Suite**
Panel Question	**Should Children Have the Same Rights as Adults to Pituitary Tumour Specialists?**		**Should Children With Brain Tumours Have Enhanced Access to Rehabilitation and Specialist Education?**	Elwin Harewood
12:00 – 12:15	Time to Commission Children's Pituitary Tumour Care: The Case for Craniopharyngioma - Mr Simon Cudlip [Pituitary Surgeon, Oxford]		Meeting Every Child's Needs: How To Access Special Educational and Health [EHCP] Support - Dr Bidishi Lahoti [Community Paediatrician, Guys Evelina]	Art Therapy
12:15 – 12:30	Time to Commission Children's Pituitary Tumour Care: The Case for Pituitary Adenomas - Prof Marta Korbonits [Pituitary Physician, Barts and Queen Mary University, London]		Meeting Every Child's Needs: Are NeuroDisability Specialists the Missing Link? - Dr Jill Cadwgan [Neurodisability Paediatrician Guys, Evelina]	
12:30 – 12:45	Time to Commission Children's Pituitary Tumour Care: The Case for a Formally Constituted National Advisory Panel and Registry – Dr Hoong We Gan [Paediatric Endocrinologist GOSH] On behalf of GOSH HPAT Virtual Advisory Team.		Meeting Every Child's Needs: Case Studies of Success Using an Early Enhanced Multidisciplinary Approach Drs Denise Crozier and Jane Williams [NeuroDevelopmentalists] [Nottingham Children's Hospital]	
12:45 – 13:00	**Speaker Panel Discussion with Prof Darren Hargrave [paed neurooncologist, GOSH] and Dr Helen Spoudeas** [Paediatric neuroendocrinologist GOSH [retird] SUCCESS Founder] **led by Mr Kristian Aquilina** [paediatric neurosurgeon GOSH]		**Speaker Panel Discussion with Derek Thomas MP [Brain Tumour APPG chair] led by Dr Jane Williams** [Neurodevelopmental Paediatrician, Nottingham and SUCCESS Trustee]	

13:00 – 14:15 Cavendish and Max Rayner Foyer	**NETWORKING LUNCH** Enjoy Lunch, Visit 'Destination '' Lounge and **Ask Questions of The Experts and Expert Survivors!**		
NeuroDevelopment /Rehabilitation **Occupational Therapy** **NeuroPhysiotherapy** **NeuroPsychology.** **Visual Impairment** **NeuroPsychiatry** **NeuroEndocrinology**	Drs Jane Williams / Jane Cadwgan / Bidishi Lahoti / Denize Crozier Pamela Anderson / Katy Strudwick Daniel Bell Dr Charlotte Malcolm, Prof Naomi Dale Drs Ashley Liew, HoLan Liang, Drs Manuela Cerbone, Ritika Kapoor,	**NeuroOncology** **Neurosurgery** **Employment Law** **Success Survivors** **Success Charity** **Success Patron** **Parliamentarians**	Prof Darren Hargrave, Messrs Aquilina, Cudlip, Lee Harding Laura, Youssef, Olivia, Grace Dr Helen Spoudeas and Trustees Dominic Grieve KC Lord Sandhurst, R Hon Derek Thomas MP
14:15 – 15:15	**Parallel Session 3**	**Breaking Down The Barriers**	**Craft Breakout**
Guy Whittle Theatre 1. **Max Rayner Theatre 2.**	**1. Mental Health and Psychiatric Needs; Lightening the Shadow**	**2. Access to Education and Work; Overcoming Barriers Interactive Workshop for and by Survivors**	**Lower Floor Training Suite**
	Chair: Prof Darren Hargrave [neurooncologist GOSH]	**Survivor Lead: Matt Tozer - Facilitator: Doug Stewart**	Elwin Harewood
		Panel: Professional Lawyers, Educationalists, Occupational Therapists, Survivors	Art Therapy
14:15 – 14:30	The Role of Neuropsychiatry and Medication in Supporting Mental Health after Acquired Brain Injury; Dr Ashley Liew [NeuroPsychiatrist Guys, Evelina]	Climbing Mount Everest: Two Survivor Perspectives of the Summit Matt Tozer and Tanya Bass [SUCCESS Peer Ambassadors]	
14:30 – 14:45	The Many Endocrine Shadows of Deep Hypothalamic Injury - Dr Manuela Cerbone [Paediatric NeuroEndocrinologist, GOSH]	Legal Rights to Accessing Education and Health Support - [Speaker TBC]	
14:45 – 15:00	Visual and NeuroBehavioural Needs Arising from Deep Midbrain Injury Multisystem Rehabilitative and Educational Support for Every Child Prof Naomi Dale – Neuropsychologist for Visual Impairment, GOSH]	Legal Rights to Accessing Employment Lee Harding [DLA Piper and SUCCESS Parent]	
15:00 – 15:15	Supporting Children and Parents: What Complex Neuropsychology Assessments Uncover about Remediating Focal Cognitive Brain Injury. Dr Charlotte Malcolm [neuropsychologist GOSH TBC]	The Role of Occupational Therapy Assessments in Supporting School and Work Placements - Pamela Anderson [Occupational Therapist, The Learning Centre]	
15:15 – 15:45 Central Atrium	**CELEBRATORY CAKE & FIZZ on** **Decisions Taken**		
15:45 - 17:00	**KeyNote Session 4**	**Setting A Successful Course**	
Guy Whittle Theatre	**Effecting SUCCESS Survivorship Hubs, Commissioned Pathways and Transformational Change** **Chair: Dominic Grieve KC**		
15:45 – 17.00	**Question? What More [Registry/Economic/Health/Social Care] Evidence Would Convince NHS England to Commission Services?** **Panel: R Hon Derek Thomas MP, Lord Sandhurst KC, Mr Kristina Aquilina, Prof Darren Hargrave, Dr Helen Spoudeas, Dr Jane Williams, Survivors**		
15:45 – 15:50	Neurosurgical Case for Formally Constituted National Weekly Expert MDT & Referral Panel for all New Pituitary Tumour Cases -		Mr Kristian Aquilina
15:50 – 15:55	Neuroncology Case for Commissioning Bespoke Pituitary Tumour Surgical and Medical Care; The Role of the CCLG		Prof Darren Hargrave
15:55 - 16:00	NeuroDisability Case for Specialist Recovery Services - Endorsing and Implementing the SUCCESS Recovery Pathway		Dr Jane Williams
16:00 – 16:40	**Panel Discussion:**		
	A Medico-Legal Perspective and Cost-Benefit? - Lord Sandhurst KC	What Can Parliament Do ?	Derek Thomas MP
	What Can Clinicians / NHSE /CCLG Do? -Drs Spoudeas Williams / Prof Hargrave	What do Survivors Think?	Hannah Harding / Youssef Ghanem
16.40 – 16.45	Identifying Next Steps and Creating a 'CHANGE' working party		Dominic Grieve KC
16.45 - 16.50	Closing Remarks & Participant Feedback		Dr Helen Spoudeas
16.50 – 17.00	**A Film of What You Said Throughout The Day**		**The 'Survivor Voice'**