

M THE MAYPOLE PROJECT

NEW MENTAL WELLBEING SERVICE FOR FAMILIES AFFECTED BY BATTEN DISEASE IN PARTNERSHIP WITH THE MAYPOLE PROJECT

The Batten Disease Family Association (BDFFA) is pleased to announce the launch of a holistic new wellbeing project, in partnership with The Maypole Project. The two charities have entered into a 3-year partnership, incorporating the new Sibling Sanctuary project that started last month.



The Maypole Project has been providing emotional and social support to families who have a child or children with complex medical needs since 2003. The charity has been working alongside the BDFFA for more than 5 years supporting families at the

annual conference and more recently at the Virtual Cuppa, plus supporting team members.

"In this time The Maypole Project has developed an in-depth understanding of how the diagnosis of a child/young person in the family with Batten disease turns everyone's lives upside down, bringing in a new unfamiliar world of treatments, and teams of professionals," says Sally Flatteau Taylor, founder and CEO. *"As everyone is unique and has different emotional response to such impacts The Maypole Project's services are designed to be tailored to everyone's needs. The project's overarching aim is to*

provide responsive emotional and social support services which are confidential, professional, holistic and ongoing."

"The BDFFA is delighted to be able to offer this invaluable new mental wellbeing service to families as well as Sibling Sanctuary," says Amanda Mortensen, CEO of the BDFFA. *"The Maypole Project's holistic approach and understanding of the challenge families face in their journey with their children with Batten disease mean their team can offer focused support for families from the point of diagnosis."*

Funding has been secured from True Colours Trust, CAF Resilience Fund and family led Pedal4Memories. The BDFFA will be seeking further funding going forward to carry on this important work.

Services include: one to one counselling, couple therapy, groups, children's therapies and specialist activities for siblings. As part of this new partnership, these services are free of charge to families. Families can also access low-cost Maypole inclusive activities for all the children in the family.

How do I access The Maypole Project's services for families affected by Batten disease?

- Call The Maypole Project directly: **01689 889889** (24/7 answerphone)
- Ask your BDFFA family support officer (Wendy or Cathy) to refer you confidentially
- Ask Rebecca Bower, Clinical Nurse Specialist at Great Ormond Street Hospital (GOSH) to refer you confidentially.

If you have already referred to The Maypole Project for specialist sibling groups and highlighted your wish to access emotional support this will be passed across to that team who will be in contact unless you inform us otherwise.



BARBARA COLE

Long term education specialist Barbara Cole is retiring from the BDFFA after 16 years with the charity. Barbara's expertise and dedication over the years in her work supporting our families has been exemplary. *"It has been an honour, a pleasure and a privilege to have worked with our wonderful children, young people and families over the years,"* says Barbara. *"I am so glad that I have been able to support so many families in getting the best possible educational support for their wonderful children and young people."*

"Over the years she has worked tirelessly in supporting families through the maze that is the education system, doing her best to ensure our children receive the support they needed - her Batters knowledge and understanding has been key," adds founder and trustee Pauline Docherty. *"She is known and loved by so many families and will leave a gigantic hole in the organisation that will be difficult to fill. Barbara has had a difficult time with illness over the last couple of years and even through her illness, carried on supporting families. I send my love and very best wishes to Barbara and hope that she enjoys her 'BDFFA retirement' - I'm sure her grandchildren will be keeping her busy!"*

We are sure families will join us in thanking Barbara who will be very much missed.

FUNDRAISING UPDATE

From Liz Brownnutt, our new Head of Fundraising!

Hello everyone, things are looking busier in the fundraising department, with events that were cancelled last year, now rescheduled to take place later this year. We found out this week that we have 5 confirmed places for the London Marathon taking place on Sunday 3rd October. This is great news and a number of people have registered their interest in running for the BDFA, so we are sure that the places will be filled very soon!

We also have 4 confirmed places in the Royal Parks Half Marathon event taking place on Sunday 10th October in London. Two of these places have been filled and we are still looking for 2 more people to take up this challenge on our behalf, so please do spread the word!

I would love to hear from anyone who is interested in undertaking an event on our behalf. I can certainly guide and support in all of that, so please do get in touch and encourage others to contact me directly. Also, we hope to launch a BDFA fundraising event later this year around the Batten disease Awareness Day. More news of this to follow, but we do hope it will attract a lot of support!



In the meantime, I am writing to Trusts and Foundations for grant support for the BDFA and families can help with this by sending in photos and quotes/stories if they would like to. This would really help funders to see the reality of Batten disease and the need for the BDFA's work.

Please do get in touch with me directly if you can help with that **07745 210212** or email lizbrownnutt@bdfa-uk.org.uk

Thank you for all your support in fundraising!

NEW BDFA CHAIR



We are delighted to announce that Dr Zlatko Sisic has become the new BDFA Chair. Zlatko has joined the Board of BDFA as the Medical and Scientific Lead in February 2020. He graduated from the Medical School in Belgrade in 1991 and spent 4 years working in Belgrade Accident and Emergency Department before coming to the UK to continue his post-graduate studies. Zlatko obtained a degree in

Chinese Medicine and Acupuncture in 1998, Masters in Business Administration in 2006 and Diploma in Pharmaceutical Medicine in 2020.

Zlatko joined the pharmaceutical industry in 2000 and has been involved in bringing medicines to patients suffering with ultra-rare disorders such as pulmonary hypertension, hereditary angioedema, mucopolysaccharidosis to name a few. Through his work in pharmaceutical medicine, Zlatko gained significant knowledge and experience in adult and paediatric neurology and diseases such as cerebral palsy, cervical dystonia, stroke and epilepsy.

Between April 2014 and January 2020, Zlatko worked in BioMarin where he was the Lead Medical Director for CLN2 and Brineura[®]. Zlatko was part of the team that successfully negotiated access to Brineura[®] to the UK patients. During his time in BioMarin, Zlatko developed lasting professional relationships with the leading international experts in NCL disorders.

In 1992 Zlatko was diagnosed with a very rare and life-threatening condition that has had a lasting impact on him and his family. Through his own experience of suffering from an orphan disease, Zlatko has developed thorough understanding of the needs of both patients and their families. It is this unique combination of Zlatko's knowledge, experience and professional relationships that makes him an ideal person to take the role of Chair of the BDFA.

Please join us in wishing Zlatko a successful career with the BDFA.

BDFA founder **Pauline Docherty** is stepping down as acting chair but will continue on the board as secretary for the next year. Thank you Pauline for all your dedication over the years.

WE'D LOVE TO HEAR FROM YOU

The BDFA will be introducing regular newsletters and ideas from the community are very welcome.

CONFERENCE UPDATE

Unfortunately, we need to postpone our family conference to 11th and 12th June 2022. The conference will run in Batten disease Awareness Week, as Batten disease Awareness Day is 9th June. This is because of the ongoing pandemic. We do not feel families will be ready to meet in person by October of this year. This conference will be held at the Crowne Plaza, Stratford, as before. We realise it will have been many years since we have been able to get families together.

We will hold a virtual AGM in May and a one day virtual conference in October, dates TBC. Any queries, please email Lisa at admin@bdfa-uk.org.uk