

Chair's Report

I am pleased to present our Annual Report for the year ended October 31st 2017.

In the past 12 months we have had to face a significant number of challenges. Although our general running costs were kept to a minimum to enable us to operate and provide a service to our members, we have always relied heavily on medical company sponsorship and two major annual fundraising events.

When I started as Chair in mid 2017, it soon became apparent that we had significantly less sponsor income than in previous years, the fundraising ball was not well attended and we were unable to use our RideLondon100 cycle slots. The Trustees were very concerned that our charity was at risk of closure.

During the second half of 2017, we conducted a thorough review of our finances, led by Lloyd McAllister, our new treasurer, focussing on minimising spending and accurate cash flow forecasting. Ken Edwards worked very closely with our sponsors to ensure we would meet their needs and maintain our important relationships with them into 2018.

On the income side, after a five year wait, it was providentially our turn to have one ticket to run in the 2018 London Marathon - and we found the right man in Martin Marafko to run for us, even though it was his first marathon! We are also very fortunate to have a special group of individuals who have rallied round to fund-raise including (but not only): 100km non-stop relay rowing in a garage, spiritual psychic events, pageant competitions, coffee mornings and a retail outlet which promotes our charity to its customers and not forgetting our patron's Dan Wood's amazing tandem parachute jump in support of our charity. Ride London 2018 was a great success for us, as was the 2018 Mitrofanoff Ball - the most well-attended ball in the charity's history, organised by Jo Lightning, who also happens to be our legal and compliance expert.

Towards the end of 2017, we also faced another tough challenge. Kyla, the charity's founder, decided to step down. Having been at the centre of the charity since its inception, all the Trustees had taken on their roles because of Kyla's vision, enthusiasm and heartfelt need to help those with a Mitrofanoff. However, we were very fortunate that Kyla's Mitrofanoff administrative role was taken on by Neil Lightning, and our charity's office was up and running smoothly within days of the handover. This includes the vitally important function of managing incoming calls from our members who may be seeking medical information (ably supported by Sharon, Angela and Louiza - our specialist medical support team), experience-led information, or a listening ear to deal with the complexities of managing a Mitrofanoff.

We continued to service the Mitrofanoff community by holding two PEDs - in Autumn 2017 in York and in Spring 2018 in Portsmouth. Our Portsmouth event was particularly well attended by children and it was a pleasure to see the very natural interaction between the older and younger age groups discussing all aspects of managing a Mitrofanoff. These events are ably supported by the Mitrofanoff band of volunteers who are integral to making these events welcoming and enjoyable.

Our social media presence, ably managed by Rachel Wall our Marketing manager, goes from strength to strength. The charity's closed Facebook group of over 1,300 members is continuing to provide a place where our members with a Mitrofanoff can interact with each other and provide a practical, supportive experience led by the Mitrofanoff community itself. We are delighted to report that we have modernised our website technology, spearheaded by our Trustee John Thatcher, which will enable us to more frequently update the information provided with useful data for our members. In its first month the new website attracted over 1,000 users.

One important, albeit reluctant decision we needed to make was to remove from the charity's articles of association the need to hold an annual general meeting. Every year fewer and fewer members were able to attend citing distance, cost of travel, health concerns etc. Unfortunately this meant that we were in danger of not achieving a quorum and thereby invalidating the AGM, a legal requirement. Therefore, after taking legal advice, we amended our articles of association in order to communicate this information via our website. We are also as keen as before to get feedback and answer all questions. So please take the opportunity to email us using our office email address info@mitrofanoff.org.uk and your query will be responded to by the most appropriate Trustee.

Finally, it is important to mention the work largely undertaken by Jo who has ensured the charity is up-to-date in its data protection policies, specifically in the area of GDPR, recently introduced legislation.

Looking forward to the coming year, we need to further improve our website's format and content, and ensure that the information we publish is as easily accessible and useable through a laptop as by way of a mobile phone. Working together with other charities and sponsors, we are planning to produce a Mitrofanoff DVD intended to help newbies and current users alike. As our next fundraising ball will not take place until June 2020, we must work hard to continue our charity's fund raising efforts in 2018/2019.

So, in summary, my first year as Chair has been challenging, but I am pleased to be able to say that we now have the foundations in place to provide a helpful service to our members. My fellow Trustees and I will continue to work hard to improve all aspects of the charity's service and I look forward to meeting many of you throughout the year at future Charity events.