

## Utopia Inaugural Charity Golf Day 19 May 2008

The Utopia group of companies was established 2004 with Utopia Works by Kevin Mashford. In 2005 Total Utopia was established as an Interior Design and Fit-out contractor by Kevin Mashford and Dieter Wood who together have developed the Utopia group of companies to £6 million turnover.

Having had seven sets of major heart surgery Kevin Mashford set out to raise cash for a charity called GUCH (Grown Up Congenital Heart Patients Association) [www.guch.org](http://www.guch.org) The charity supports young people and adults with congenital heart disease. 'At first we thought one or two of our suppliers and contractors would sponsor the golf day, but I have been overwhelmed by the support we have had'. The golf day at The Kendleshire Golf Club in Bristol has been a huge success and has raised £6,000 for the charity which was presented on 19 June at Engineers House, Clifton, Bristol to Beth Greenaway (Chairman) Of GUCH.

The day consisted of bacon rolls then 18 holes of good spirited golf. Dr Mark Turner who is one of the GUCH specialists at the Bristol Royal Infirmary then presented some video footage of the pioneering keyhole valve replacement surgery after dinner! Kevin Mashford commented that 'although it was a risky strategy following a beef wellington, I have never seen so many silent, open mouthed faces transfixed on the screen. I thought it important to show everyone that the cash raised really does go on to do quite amazing things for peoples lives'.

Full details of the Inaugural Golf day are on [www.total-utopia.com](http://www.total-utopia.com) with thanks to everyone who sponsored the day.

Below is key GUCH information. At the cheque presentation Kevin Mashford was moved by stories of lack of exposure of GUCH. So many young adults are being miss-diagnosed due to lack of understanding. The 'survival rate' of children born with congenital heart defects is increasing with ground breaking advances in medical procedures. As these children enter into adulthood if they live in an area without a GUCH trained cardiologist they are simply discharged by paediatric hospitals and are without support. One of GUCH's aims is to have more centres around the country. This can only happen with funding...

## **Medical Advancements**

Advances in cardiac medicine during the last 40 years have meant that a new group has now emerged in our society. Children who once would not have survived have become adults. This has led to new thinking about what is appropriate as far as hospital care is concerned, and there is a movement throughout health services to provide specialist units for adolescents and adults with congenital heart problems - which is often hindered by lack of NHS funding.

## **The Difficulties To Be Faced**

To most of us, many of these young people may not look particularly disabled - perhaps just a little blue in the face and hands. The reality is that they face physical limitations and an uncertain lifespan; some may

need a heart transplant. For many, their normal development and education has often been impeded. They frequently feel lonely and isolated.

The Grown Up Congenital Heart Patients Association's vision was, therefore, to create a national support network run by and for young adult congenital heart patients. This network would allow similar experiences to be shared and practical advice to be offered on issues like insurance, employment, welfare benefits. Above all, it would encourage congenital heart patients to help and support each other.

## **Formation of the GUCH Patients Association**

In 1993, work began to inform consultants and nursing staff at the specialist heart centres around the country about the Association. Members were gathered via hospital staff and personal contacts. 1993 also saw the production of the first newsletters, two a year initially. This has now increased to four issues a year. There was a great deal of enthusiasm for the Association, particularly amongst patients at the Royal Brompton Hospital, and many volunteered their services to assist in the running of the organisation.

In 1995 the GUCH Management Committee was established. They provide advice and guidance to the Trustees and Officers of the GUCH Patients Association on all aspects of the day to day running and management of the Association. The Committee is elected by the Association's members every two years and is accountable to the Trustees. The Association's first full-time National Director, Mavis Moore, was appointed in September 1999.

The aim of the Association is to provide support, but more importantly, to enable full adult living for this relatively new medical community which is growing by about 3,000 each year. They have survived as a result of advances in surgery and medicine for congenital heart disease. However, their disability leads to difficulties and disadvantage; they have problems securing the essential things in life such as employment, insurance, mortgages. Currently it is estimated that there are over 100,000 GUCH patients in the UK.

## **Our Aims**

To encourage GUCH patients to help and support each other by sharing knowledge and experience.

To provide information and advice to improve the management of problems - general and medical.

To provide support and encouragement for all GUCHs, their partners and families.

To work with health care professionals to raise awareness of GUCH patients and their needs within health services.

To organise events and provide opportunities for GUCHs to meet socially.

To promote awareness and educate social care professionals, employers, insurers and the general public about the existence and the needs of Grown Up Congenital Heart patients.