Project title: 24 Weeks Plus
Location: London wide
Date: July 2001 onwards
Funding: King’s Fund Millennium Award

The context  According to the premature baby charity, Bliss, seven per cent of babies in the UK are born prematurely (at less than 37 weeks), and around 18,000 of these require neonatal intensive care. Survival rates for these babies are related to their gestational age at birth: babies born at 23 weeks have a 17 per cent chance of survival; at 24 weeks, a 39 per cent chance; and at 25 weeks, a 50 per cent chance.

With survival rates so low, caring for a premature baby can be very traumatic for the parents. Having been through this experience themselves, Millennium Award winners Joanne Crow, Rebecca Hankins and Karen Hawkins decided to set up a project called 24 Weeks Plus to provide support and advice to other parents of premature babies, and to raise awareness of parental needs among neonatal staff.

The Millennium Awards scheme  Between 2001 and 2004, the King’s Fund worked in partnership with the Millennium Commission to offer grant-funding, support and training to 255 people working at community level to improve the health of Londoners. Each person received a maximum £2,000 cash grant from Lottery funding, and took part in a 13-day King’s Fund leadership development programme designed to build skills in project management and networking.

This is one in a series of case studies exploring how individuals living in London have used the King’s Fund Millennium Awards scheme to make a real difference to the health of others in their communities.
Karen Hawkins, Joanne Crow and Rebecca Hankins met in the neonatal unit at the
Royal Free Hospital in north London while caring for their babies – all of whom were
born extremely prematurely at 24 weeks. As a result of their experiences, these
women felt that there was a lack of support available to those affected by the
trauma of premature birth. To address this issue, they decided to set up a project
called 24 Weeks Plus. This consists of an email service offering advice and support
to parents who are caring for a premature baby; leaflets and a website providing
relevant information; and educational talks aimed at neonatal health professionals
to raise awareness of parents’ perspectives.

The interview

Why did you get involved?

We met each other on the neonatal unit at the Royal Free Hospital in north London, while caring for our premature
babies. It was around the Christmas and New Year of 2001/02. During that time the three of us formed a really intense
friendship. Rebecca’s daughter, Thaila, was born at 24 weeks; she died three weeks later. Karen’s twins, Molly and
Jake, were also born at 24 weeks; Molly died a week later, and Jake battled on for several months of operations until
passing away, with sad irony, on his official due date. Joanne’s daughter, Hannah, was born at 24 weeks, but managed
to survive and is now a happy, healthy toddler.

It was an eerie experience, spending months in a neonatal unit – like living in a bubble. Looking back it was the support
we gave each other that enabled us to get through that period. Just knowing that someone was there, holding your
hand, knowing what you were going through, made things somehow easier to bear.

Having been through those experiences ourselves, we decided to set up 24 Weeks Plus to help other parents in similar
situations. Although there are some good charities, such as Tommy’s and Bliss, involved in tackling the issues around
premature birth, we felt that there was not enough support for us during our time in the neonatal unit. For example,
entering the unit for the first time, we all felt alienated and afraid. With our project we hoped to make this experience
more comfortable for parents by providing them with advice and information when they need it most.

We also wanted to change the way that parents are treated on the ward. As the parent of a premature baby, you can feel
extremely powerless because you are forced to hand over your baby into the care of others. However, there are a number
of things hospital staff can do to make this experience easier for parents that are simple to do and don’t cost any money.

What is your project?

Our project consists of a number of different activities. The first is an email service offering help, advice or a shoulder to
cry on to those who have had a premature baby. This is our main point of contact with people; we don’t offer telephone
support. Karen is our administrator, and forwards the emails to one of us, depending on the nature of the problem and
which of us might be best placed to help. To promote the email service, we designed and printed some posters, using
some of the money from the Millennium Award. We then distributed these posters to 20 neonatal units across London.

We have also prepared leaflets, listing 24 points of useful information for parents of premature babies. The leaflets
include tips on how to position and touch your baby, and advice about talking to the doctors and nurses. Once
the leaflets are printed, we plan to distribute them to as many hospitals in London as possible. Karen is currently
developing our website, which will provide another source of guidance to parents. Rebecca is our researcher and
has come up with some brilliant material that we can use. The information is ready to be posted on the web, but
the site isn’t complete yet.

As well as offering advice and support, we also want to raise awareness among hospital staff of how they can help
the parents of premature babies. So far we have given a couple of talks about our experiences to groups of health
professionals, including a meeting of neonatal nurses from the UK and the USA. Joanne tends to do most of the public speaking and promotion work because she had the longest contact with neonatal staff while her daughter was in hospital.

As a result of these talks, it has become apparent that some nurses don’t realise the sorts of questions that go through parents’ minds. We’ve realised that we can play a crucial role in educating doctors and nurses about how to approach parents, and how to treat babies in ways that won’t cause anxiety or stress to the parents. For example, when a nurse puts a cold stethoscope on a sleeping baby, the mother can feel traumatised, knowing that her baby will feel cold. Once aware of this, the nurse only has to warm the stethoscope up with her hands for a few seconds to avoid causing stress to both mother and baby.

How did you get people involved?

Officially, the main way that we’ve encouraged people to get involved in our project is through the posters that we’ve distributed to various hospitals. However, we believe that we have had more people contact us as a result of word-of-mouth recommendations than from publicity. Through the activities of 24 Weeks Plus, we’ve now established links with various London hospitals. In future, we’re hoping to take our work into other hospitals, as well as speaking to other groups of health professionals, in order to spread our message further.

What help did you need?

The head occupational therapist from the Royal Free Hospital, Betty Hutchon, helped us to write our leaflets. We came up with the 24 main points and then Betty, who is an expert in her field, made sure that the information was accurate.

The BBC used Joanne and Rebecca in their research for a film called *This Little Life*, which was about the experiences of a couple coping with the premature birth of their baby. Since then we’ve kept in close contact with the production team, and have been involved in providing a helpline following the screening of the film. As a result, we’ve made some useful media contacts, who have helped us to generate further publicity for our project.

The Ilford Council for Voluntary Services is also working with us on the website and they’ve been really helpful.

What challenges did you face?

Initially we didn’t realise how much work there was to do. We had lots of ideas but many of them simply weren’t realistic. We didn’t think through how many people we would be targeting or how we would make the money. Participating in the King’s Fund leadership programme helped us to realise that we were trying to do too much too soon. The facilitators encouraged us to slow down and start thinking things through more logically.

Another challenge has been persuading people that we’re not a fly-by-night group, that this project is not something that we’re going to walk away from as our lives improve. We want to show people that we’re serious by becoming a registered charity and getting celebrities on board to help promote our work.

What lessons did you learn?

We’ve learned that setting up a project is an awful lot harder than we anticipated. When we began, we knew that 24 Weeks Plus was going to be a long-term project but I don’t think we realised quite how long it would be before the project became established: we’ve been operating for more than a year already, but it’s going to be at least another couple of years before we start to see results.

Because of the sadness involved in our work, and because the work is so closely related to our own experiences, it can feel extremely personal. Realising that other people are not as passionate about our project as we are has therefore been quite difficult. We have had to learn when to open and when to close our mouths, and to appreciate that other people don’t always share our opinions.
Where does your project go from here?

Hopefully 24 Weeks Plus will be a long-running project. We want our posters to be displayed in fertility units, antenatal classes, baby clinics and childcare centres to raise awareness of our work. We also want to continue just being there for people, because for the parents of premature babies, it can feel like they’re the only ones in the world to go through something so traumatic.

The next step is to find ourselves an office that, between the three of us, we can run from Monday to Friday (although we will still need to sort out childcare). Our other plans include completing the website, educating more health professionals about parents’ views, and becoming a registered charity. We’d also like to publicise our message by involving celebrities in our cause, although that will only come once we’ve got our charity number and they feel assured that we’re serious.

Another long-term aim is to buy a house by the sea that we can offer to families traumatised by a premature birth. When a baby is being cared for in a neonatal unit, the family is often split, with the mother spending all her time with the baby, away from her partner and other children. At the end of that period, the family desperately needs some time to reconnect, particularly if they have lost their baby.

What advice would you give to others?

Before taking on a project, you’ve got to estimate the effect that it will have upon your life. Even if what you’re doing is only short-term, you’ve got to weigh up how much it’s going to cost you and those around you in terms of time, energy and money. Establish the boundaries of what you will and won’t do, and stick to them. If you don’t, you could end up making more enemies than friends.

Although you can’t foresee the future, and things will inevitably change, plan your project carefully and do what you can to prepare for any difficulties that may occur. If we’d sat down and thought through our project properly, we would have realised that 24 Weeks Plus was going to be much bigger than we’d expected.

Interested?

The Millennium Awards scheme has now closed, but the following funding opportunities remain:

**King’s Fund grants** We offer about £1.5 million a year in grants to London-based community-based organisations working to improve health and health care (t: 020 7307 2495, e: grants@kingsfund.org.uk, w: www.kingsfund.org.uk/grants).

**Unltd** This is a national body set up to provide grants, training and support to individuals working to make a positive difference in their communities (t: 020 7566 1100, e: info@unltd.org.uk, w: www.unltd.org.uk).