

## **Diana Children's Community Service**

### **20<sup>th</sup> Anniversary Appeal**



The Diana Children's Community Service cares for children with life-threatening and life-limiting conditions in their own homes. The dedicated team, which works across Leicester, Leicestershire and Rutland, includes nurses, physiotherapists and play specialists who provide both physical and emotional support to these very poorly children and their families throughout their illness and at the end of life. The Diana Children's Community Service is celebrating its 20<sup>th</sup> year this year and we are launching this appeal as part of the celebrations and to raise awareness of this valuable service which is little known in comparison to the local children's wards and hospice.

In preparing this appeal, members of the team were asked what would have the greatest impact on the care they provide to local children and their families. They were asked to only select items which are over and above what is possible within NHS budgets.

With your support this appeal will greatly enhance the care our teams are able to provide. If you would like to be involved with the appeal or if you would like more information then we would love to hear from you.

#### **1. End of life bundles: £600 each - three bundles would be amazing (£1,800)**

The Diana Service provide end of life care as part of a range of services for children and young people who have nursing needs within Leicester, Leicestershire and Rutland. When a child is at the end of life the Diana Service activate 24/7 On-Call so the family are supported throughout this difficult time. In order to do so the Diana Service take a lot of equipment and supplies to the home to anticipate the support they may require. It is often difficult obtaining all of the equipment needed as there is little time to plan for a child at the end of life. Having these readily available bundles will help to improve the care we deliver children and their families at homes, in a timely manner.

Each bundle would contain one of each of the following items:

- Repose Mattress (172.80 each inc VAT)
- Repose Pillows (£154.80 each inc VAT)
- BT Video Baby Monitor 6000 (£109.99)
- Clip on fan (£14.89)
- Trunki trolley to take equipment to families £50

- Sack trolley to store equipment in the home £20
- Trolley bag to transport end of life equipment and keep in family home £47.99
- Storage draws for end of life equipment in family homes £26 each

## **2. Additional equipment for end of life care:**

**Vouchers for Finger Print Jewellery** – need approx. 10 a year x £100 each = **£1,000** (Oncology Children already get £250 vouchers from another charity)

Over the years there have been several charities who provide funding for Oncology families to receive finger print and hand print silver jewellery when the child is at end of life. The Diana Service would welcome any funding to allow us to provide this for non-oncology families to ensure it is equitable for all. The other charities offer £250 for each family which we appreciate is a lot of money therefore would be happy for any donation. Generally the cheapest item is £60.

**Cooling equipment for after a child has died:** Cuddle Cot **£1,750** for babies and Mini 170 Cuddle **£5000** for children.

Families occasionally ask for their child to stay at home after they have died, for a day or until the funeral. In the past we have given advice related to keeping the rooms cool with aircon units however there is now special blankets which either go under or over the child, helping to keep them cool.

**Leaflets and packaging to keep delicate information for families** (approx. **£400** for 2 year supply)

The Diana Service provide information for families in their home to enable them to have all the information needed. This comes in the form of booklets related to care and what to do after their child has died. They are also given information related to charities who can support them. The information is very sensitive and most families would prefer to keep it close but private. Unfortunately we have limited funding to develop the booklets and folders to keep them in. Any contribution towards this would be gratefully accepted.

## **3. Days out for children with Life-limiting and Life-threatening conditions who are receiving respite care from the Diana Service: Total £438**

Our Diana Continuing Care team provide families with respite to allow them time to have a break from caring for their children who have very complex health care needs. The families need to provide funding if they want the team to take them on trips or days out. Most of the families are on low incomes therefore often do not have extra funds for this. Having funding which would allow our team to take the children on day trips will enhance their quality of life and build special memories for them and their families.

- Twycross Zoo Annual Pass for carer and child x3 (plus extra carer as some children need 2) £45 each = £130 in total
- Vue cinema passes £100
- Space centre annual pass for carer and child x 2 (plus extra carer as some children need 2) £11 each x 8 = £88
- 360 play £6 per child plus adult free x £20 passes £120

#### **4. Respiratory Physiotherapy – Clear Way Cough Assist: £3,500**

We use the clearway cough assist with our neuromuscular and neuro-disability patients. The device delivers pressure to increase lung expansion and facilitate a cough which can in turn prevent chest infections and maintain lung function. It is always our intention to help our patients to stay at home with their families and using the Clear Way Cough Assist can help avoid chest infections which could cause a child to need hospitalisation.

#### **5. Children’s Phlebotomy – iPads (x3) in blood test clinics: £930**

The children’s phlebotomy team are specially trained to take blood from children. GPs will refer children to one of the three clinics where the team are skilled at explaining the procedure and using distraction techniques to make the blood test as comfortable as possible for the child. Children are so used to having tablet devices to play games on the addition of iPads to clinic would allow the team to utilise appropriate apps and games to distract the child. Each iPad, screen protector and case with handles especially designed for a child’s grip costs £310.

#### **6. Port-a caths and Hickman line demo dolls: 2 of each type £1214**

Port-a caths and Hickman lines are thin plastic tubes which are inserted underneath the skin of the chest and are used when a patient needs to have multiple blood samples taken over a period of time or when antibiotics (e.g. for Cystic Fibrosis patients) or chemotherapy needs to be administered IV.

This can be a very worrying procedure for the child and they need to understand why they have to wear the tube in order that they leave it in-situ for as long as it is required. We use real port-a caths and Hickman lines with dolls to demonstrate procedures to children. This helps to reduce their anxiety about having the procedure done themselves as they will have had chance to see the equipment and how it works with the doll. They can see the devices being inserted as well as fluid being drawn from them or administered to them. The tubes need to be flushed every month to stop them becoming blocked so it is imperative that the child is comfortable with the procedures.

Through repeated use and cleaning these demo dolls with their lines do have a ‘shelf life’. We would like two dolls to be set up with each type of long term catheter / port.

Port-a cath: £270 each

Hickman line: £307 each

Dolls: £15 each

#### **7. Memory Boxes – 20 boxes £310**

Following the death of a child, our play specialists will provide emotional support to the child’s siblings. Creating a memory box is a really important activity to help grieving children and to capture memories which may otherwise be lost over time. The memory boxes from Winston’s Wish are ideal for this as they have three compartments to hold small objects such as jewellery, as well as a pouch to store precious photographs. They come in plain and coloured versions to allow the child to customise the box and make it unique to them and their memories of their brother or sister.

**Thank you for considering our request for support**

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