

20 very



years

1985

2005



Summer and great it is too.

Thank you to all of
you who challenge
yourselves through
fundraising, committee

work or any such, and through that help Simpsons
Special Care Babies. To all our members and
supporters:

From W. H. Murray in *The Scottish Himalaya
Expedition*, 1951. There the text says reportedly:

'But when I said that nothing had been done I erred in
one important matter. We had definitely committed
ourselves and were halfway out of our ruts. We had put
down our passage money - booked a sailing to Bombay.
This may sound too simple, but is great in consequence.
Until one is committed, there is hesitancy, the
chance to draw back, always ineffectiveness.
Concerning all acts of initiative (and creation), there
is one elementary truth the ignorance of which kills
countless ideas and splendid plans: that the moment
one definitely commits oneself, the providence moves
too. A whole stream of events issues from the
decision, raising in one's favor all manner of
unforeseen incidents, meetings and material
assistance, which no man could have dreamt would
have come his way. I learned a deep respect for one
of Goethe's couplets:

**Whatever you can do or dream you can, begin
it.**

Boldness has genius, power and magic in it!

A donation came from Willowpark School recently: Head
teacher Ann Balfour says "Lynne, Christopher and
Alexander have been working on an Enterprise Activity
module in School. Their profits came to £75.00 and
they chose to donate it to the Special Care Babies."
Three members of the school came with one their
teachers to present this to the charity.

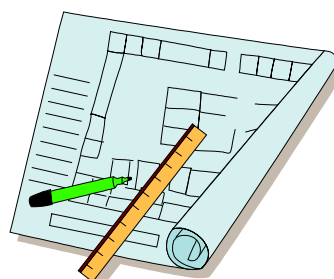
Alexander is one of our old boys!

Well done to all the team who worked so hard for us.



Football Aid has been
developed by the charity
"Field of Dreams" a
Scottish Charity, in order
to raise funds for
voluntary and charitable
organisations. Field of
Dreams is a grant-making
charity, which distributes

monies raised through
its annual Football Aid
fundraising programme.
Simpsons Special Care
Babies was contacted by Shelley at Hearts Football
Club and asked if we had a project we would like to
apply to Football Aid for a grant of £300. Of course.
The phototherapy units were being saved for and an
application form was soon winging its way to Football
Aid. We are hopeful of being successful.



**Scottish Design
Awards 2005**

**Best Building for
Public Use**

**Sponsor:
Pilkington Building
Products - UK**

Project: The Sanctuary

Architect: Sutherland & Hussey Architects

Artist: Donald Urquhart

Chaplain: Sandy Young

Project Manager: Tom Littlewood

The Sanctuary at the Royal Infirmary has been
entered for the Best Building for Public Use category
in the Scottish Design Awards 2005. Full results will
be announced at a gala dinner presentation at the
Moat House Hotel in Glasgow on Friday 27 May.

Postscript: 2nd placed.

The charity is currently saving for a newly developed brain monitor
further information on www.brainzinstruments.com. The **BRM 2
Brain Monitor** has a wide range of powerful features including
continuous monitoring, long and short term trend displays,
downloadable information to enable consultation with other
professionals elsewhere etc. Thank you for your help.



Excerpt from BabyLink — improving communication among clinicians and with the parents of babies in intensive care

A team from the Royal Infirmary of Edinburgh have developed an efficient means for keeping parents informed about the care and progress of their babies being cared for in the hospital's neonatal unit. *Dr Yvonne Freer, Dr Andrew Lyon, Dr Ben Stenson and Clare Russell* describe the system's main features.

ABSTRACT

BabyLink is an innovative approach to sharing information with parents whose babies have been admitted to a neonatal unit.

Reports summarising the clinical condition and treatment of the baby are produced automatically, at least once a day, from the baby's electronic medical notes. This does not involve any extra input from the clinical staff. The software automatically attaches explanatory information to the clinical data, to help the parents understand their baby's problems and treatments. This includes explanations of the risks and benefits of therapy given to the baby.

The reports are encrypted and posted onto a secure Internet website, the family being able to access them, using their own usernames and passwords, from a web browser anywhere in the world. The parents can post questions back to the clinical team. Baby diaries, including digital photographs, are also posted to the website.

BabyLink has been beneficial to families in communicating complex information and humanising the experience of neonatal intensive care.

Evening News 25 April 2005

Health New site is born to offer words of comfort

JENNIFER VEITCH

WHEN Stephanie and Andrew Lees discovered during a routine scan that they were expecting not one but two new arrivals, they were delighted, if not entirely surprised. Twins run in the family.

But the fact that twins are also much more likely to arrive earlier than planned did little to prepare them for the traumatic months that lay ahead. In January, Stephanie went into labour when she was

just 26 weeks pregnant - three and a half months before the babies were due.

"It was all a bit of a shock," recalls Stephanie, 28, from Port Seton, East Lothian. "I had a bit of concern, so I phoned the hospital and they asked me to come in. They checked and confirmed that I was already 4cm dilated - and my daughter was coming feet first, so I had to have an emergency Caesarean section."

The twins - Ebony, who weighed 2lb 6oz, and her brother Mason, who was only 2lb 1oz - were rushed into intensive care at Edinburgh Royal Infirmary's neonatal unit.

Both babies were put on ventilators, as their lungs were not developed enough for them to be able to breathe on their own.

"The first time I saw them, they had put them in little plastic bags to keep them warm, and they looked almost transparent," remembers Andrew, 25. "They were so small they were scary to look at. There were intravenous drips over them, and all the machines were beeping."

Stephanie and Andrew, a co-director in a family-run catering equipment hire business, have barely left the hospital since the birth - but with a three-year-old son, Jordan, to care for at home, they can't be there all the time to watch over the twins.

But thanks to new technology developed by staff at the neonatal unit, the couple can check on the twins' progress whenever they want - by simply logging on to the internet.

Stephanie and Andrew are among the first parents to use BabyLink, a secure website which ties in with the babies' electronic medical records.

Parents can access up-to-date reports about their baby's condition, with straightforward explanations of complex medical terms. The site also features informal baby "diaries", including digital photos with messages written by the staff like: "Hi Mum and Dad, Feeling good today. Looking forward to seeing you later, Love George xxx".

Access to the diaries can be shared with friends and family - the Lees have given relatives in Australia the log-in details - which can reduce the need for parents to keep updating everyone on the progress of their baby. Staff stress that BabyLink does not replace the need to brief parents - and bad news will always be broken in person.

But in its first year on trial, BabyLink has reduced parents' anxiety and better prepared them for their baby's transfer from intensive care to special care, and - all being well - their discharge from hospital.

Andrew says the site has been a great comfort when he has been at home, worrying how the twins are in hospital.

"You can't be here 24 hours a day, but if you are sitting at home you always feel that if you phone up you are being a nuisance.

"So I just go straight on the computer. It gives you the whole run-down on things like scans, X-rays, changes in body weight, how they

are feeding, whether they are breathing on their own, and it also explains some of the medical words, as well as information about the unit."

Pamela Tosh and Neil Willett, whose daughter Eva is in intensive care, and weighed only 1lb 5oz five weeks after her birth at 25 or 26 weeks, have also been impressed by BabyLink.

"When Eva was born, and for a couple of weeks afterwards, I decided to check the internet, but it was full of gloom and doom stories, and also a lot of misinformation," says Pamela, 36, a modern languages teacher from Edinburgh, who was induced after developing pre-eclampsia.

"With BabyLink, we know the information is reliable, and it's tailored to the individual baby. There is always a little personal comment about how she has been - there is that personal touch."

NEIL, 39, an administrator at Edinburgh University, adds that it allows parents to look back at information which they might not have taken in fully when it was first explained.

He adds: "My eyebrows were raised once when I saw that she was receiving caffeine. But then I read that in very small quantities, it helps the babies to breathe on their own."

For Lynne and Walter McDougall, whose first child Abby was born at the ERI last month weighing only 1lb 1oz, the BabyLink service has been invaluable.

"We go on to the site as soon as we wake up every morning," says Lynne.

Lynne, from Fauldhouse, West Lothian, who went into labour at only 25 weeks, had an emergency Caesarean.

"Walter's mum was on holiday in Tenerife when Abby was born, but she was able to see her on the computer, and it reassured her, as she was quite anxious.

"It also reminds you that there is 24-hour care at the unit, as we logged on and found out Abby had been weighed during the night.

"WE WERE REALLY PLEASED - WE FOUND OUT SHE HAD GAINED TWO OUNCES."

Personalise your e-mails:

A suggestion for us all: Why not personalise your e-mails and support SSCB as well. One of our members has allowed SSCB to include photos on our website together with their family's story. She has then included the following to be included on each e-mail she sent:

Click on www.sscb.org (click on Simpsons Babies) to see my little girl Emma Sutherland. If you have a spare fiver please donate it to Simpsons Special Care Babies. You will help save more lives. Thank you. x

THE GREAT WEE WALKS A BIG HIT WITH THE YOUNG ONES



"100's of children from all around Scotland have been taking part in the Wee walks that have been happening all around Scotland.

"The response from the young ones has been amazing." Terry Crossley, Wee walk organiser, said "they are really enjoying getting out there and being involved in fitness, bringing their families along with them. I think the goodie bag, medal & certificate are helping too..."

Young Declan Jones and Aaron Bonnes took part (with their respective families). Both families have been in touch with Gill Mitchell and are very proud of their fit youngsters. As are we. Aaron had lots of energy at the end (he had the benefit of a pushchair) but mum and dad did also. Dad did the 12 mile walk while Aaron and mum did the 6 mile walk. Dad came in 97th. Congratulations to all.

CONGRATULATIONS indeed to Grant Matheson who ran the **2005 Edinburgh Marathon** for SSCB and arrived at the finish in **301st place**. Here is Grant who is the very proud Uncle of Bailey.



Also in the 2005 Edinburgh Marathon were teams in the Hairy Haggis Team Relay featuring for SSCB:



213 Botanical Miscellany (10735)

Colin Pendry, Louise Olley, David Harris, Rob Cubey, Hatty Hughes Time: 03:37:21

235 Botanical Baby Buddies (10829)

George Sherriffs, Susan Finlayson, Jeremy Milne, Jackie Whelan, Todd Law 03:39:26

529 The Blistering Botanics (10967)

Peter Wilkie, Scott Mc Gregor, Natalie McCandlish, Jill Irving, Sam Bridgewater 04:00:47

We are so very proud of them all. AND they raised £1391.50

Donations:

We were most grateful to receive £194.20 in matched funds from the National Grid Transco Matched Giving Scheme recently. This resulted from enthusiastic fund raising by the Dargo family before Christmas.

"The children of South Church Sunday School Whitburn would like to donate their offering money this year to Simpsons Special Care Baby Unit. Just to give something back for Dawn Brown, Callum and Euan Scott all of who were born prematurely. Dawn was 12 weeks premature twenty one years ago and Callum and Euan were just under 10 weeks premature 9 years ago all weighing less than a bag of sugar. As Dawn helps us out when we are short of teachers and Callum & Euan are Sunday School pupils we would like to donate £400 to the Special Care Baby Unit as they all started their lives in your Unit. Thankfully with all the care and dedication of the doctors and nurses in the Special Care Baby Unit all three have never looked back. Dawn, Callum and Euan are some of your miracle babies."

1985 to 2005



In our celebratory year we would like to share the aims and successes of the charity with as many people as possible. We would like to have a display board with our

babies and children on telling everyone from firsthand knowledge about the work of the

Neonatal Unit and the charity. We would love to hear from anyone who would be interested in pursuing this idea. Some families generously send photographs to the Neonatal Unit for the Little Stars book and these could be the basis of our display board. Your individual story is very important and will be different and interesting to others.

Christmas cards:

In 2004 these were sent to as far afield as Manchester, Aberdeen, Brechin, Lauder, Ottery St Mary in Devon as well as Edinburgh and Lothian region. One purchaser commented on the great value represented by our cards. Our 2005 cards have now been purchased ready for sale at the end of the year. The leaflets will optimistically be at your house in August this year! Why not mark your calendar to have a look at the leaflet and buy some cards this year. Members of our merchandising group are keen to tell as many people as possible of our cards, and one idea is to send each member 3 leaflets - one for their own use and 2 to go up on a notice board at work (pin up the front of one and back of the other) to promote the cards. We depend upon word of mouth, visits to our Christmas card page on the website (www.sscb.org) and loyal customers to make the Christmas card sales a good source of fundraising for the charity.

Available from the end of August.

SSCB Wristbands:

We are proud to tell you that Simpsons Special Care Babies have added these items to their merchandise range. If you would like one, they will be available via the website towards the end of August or now by telephoning:

Rosie: 0131 477 0476 or by e-mail:

rosie@bigalentertainments.com

Alternatively:

Gill: 0131 242 2567 or by e-mail through the charity's website: www.sscb.org



£2
each

On the website soon