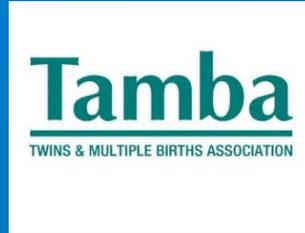


Newcastle
Biomedicine



The Butterfly Project: how can staff improve the experiences of parents who suffer the loss of a baby from a twin pregnancy?

4° Congreso Argentino de Neonatología

Buenos Aires 22-24 Mayo 2019

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Professor of Neonatal Medicine, Newcastle, UK

Newcastle Neonatal Research Team



Qualitative work with parents

- **Withdrawal of intensive care support**
- **Loss of a baby from a multiple pregnancy**
- **Palliative care – location**
- **Parent views of joining more multiple studies**
- **Aims**
 - **Better understand parental perspective**
 - **Educate, inform and improve outcomes**



'Traditional' areas of study

Practical aspects



Ethical aspects



Parent & staff experiences

Societal aspects



Life

Newcastle Neonatal Research Team



Qualitative work with parents

- **Withdrawal of intensive care support**
- Independent researcher spoke to: 17 families + 20 staff
- What did it feel like to be involved in a decision to discontinue intensive care support?
- During this study – we realized some families had suffered death of one twin
- Conducted a 2nd study focused on “twin loss”

Loss from a multiple pregnancy

- Qualitative study: parents & health professionals
- Experiences & feelings following loss from multiple pregnancy
- Complex emotions & experiences – parents & staff

Richards et al. 2015, 2016

Loss from a multiple pregnancy

We don't seem to be able to deal with both grief and joy....

We are great dealing with the grief if there is just one baby that has died and we are great at being delighted and happy when it all goes fine....

..but we are not managing the two together very well

Key themes

*“it was almost
like he’s not a
twin
anymore....”*

1. Recognise twin status
2. Acknowledge the bereavement
3. Provide emotional support
4. Provide appropriate information
5. Provide continuity
6. Offer memory making
7. Handle cot occupancy sensitively on the neonatal unit
8. Prepare parents for discharge from hospital

Complexity of the NICU environment



Complexity of the NICU environment

Jaundice & phototherapy

Central lines

Heart rate

Fluids

Oxygen saturation

CPAP, BiPAP or Hi-flow

Ventilation

Blood pressure

Urine output

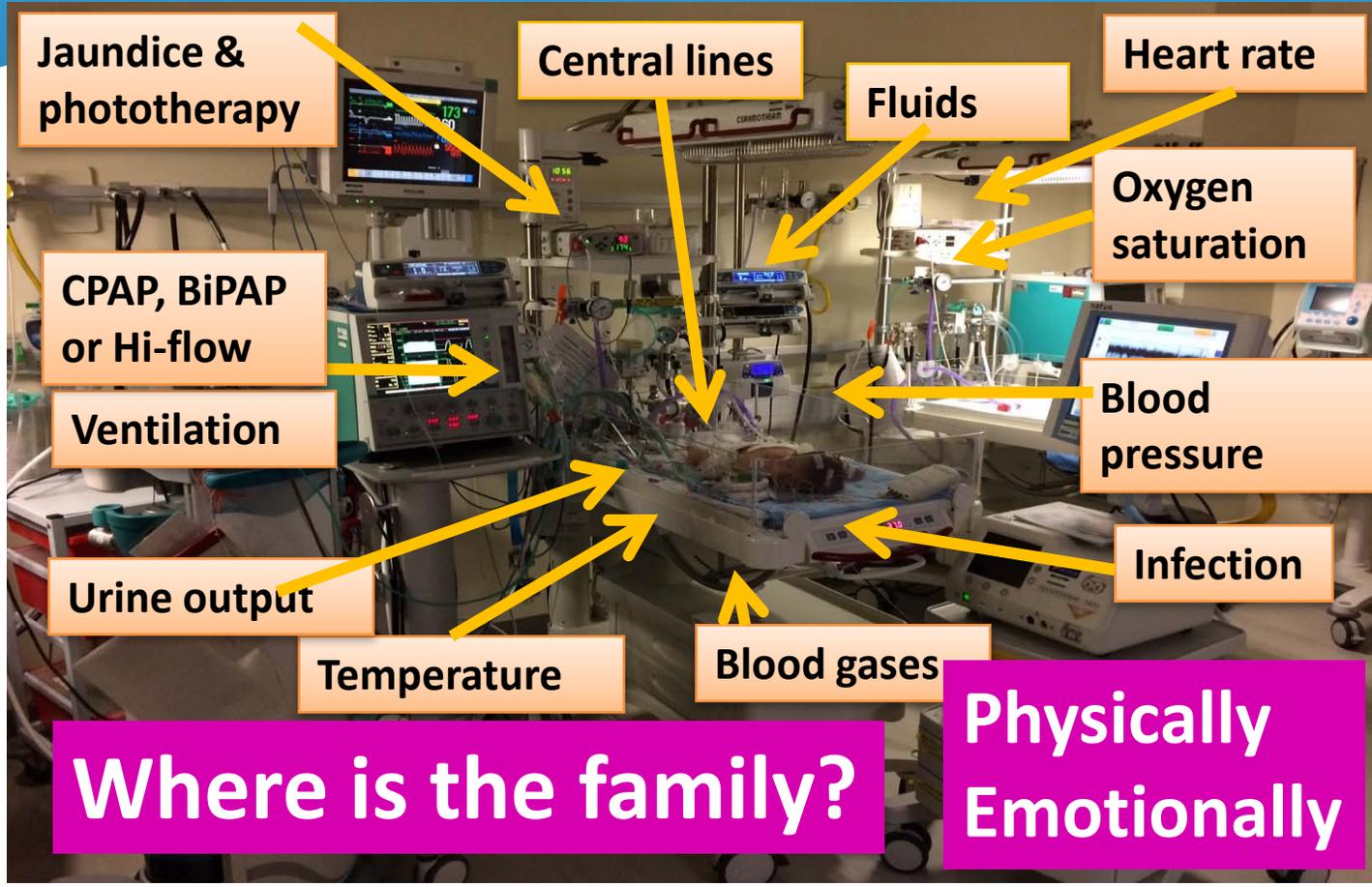
Temperature

Blood gases

Infection

Where is the family?

Physically
Emotionally



Recognise twin status

‘Nurses would ask ‘How was your pregnancy with him?’ They forget about him being a twin and everything like that’ [Mother]



Recognise twin status – what to do?

- establish what parents want
- refer to twin by name

Example to say - 'I know this must be really difficult time for you.....If you can tell me what is helpful for you, I can make sure the other staff know. If you don't know what you want us to do it doesn't matter. We can talk about it another time.'

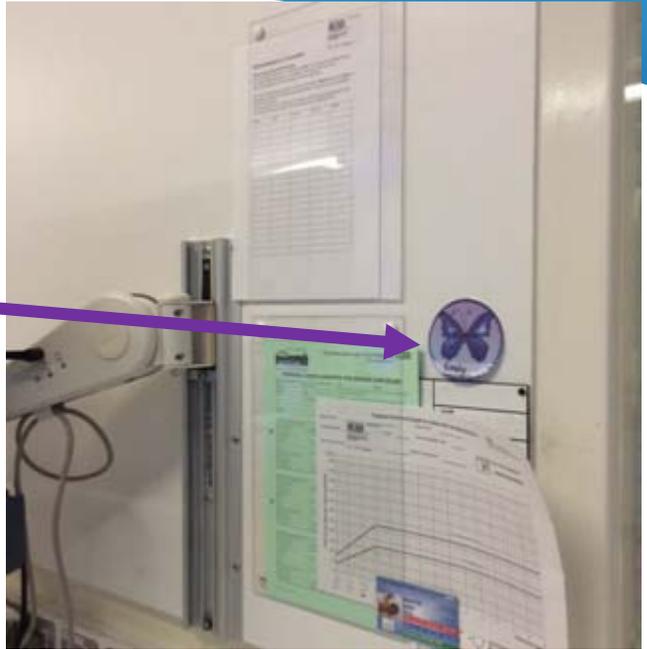
Recognise twin status

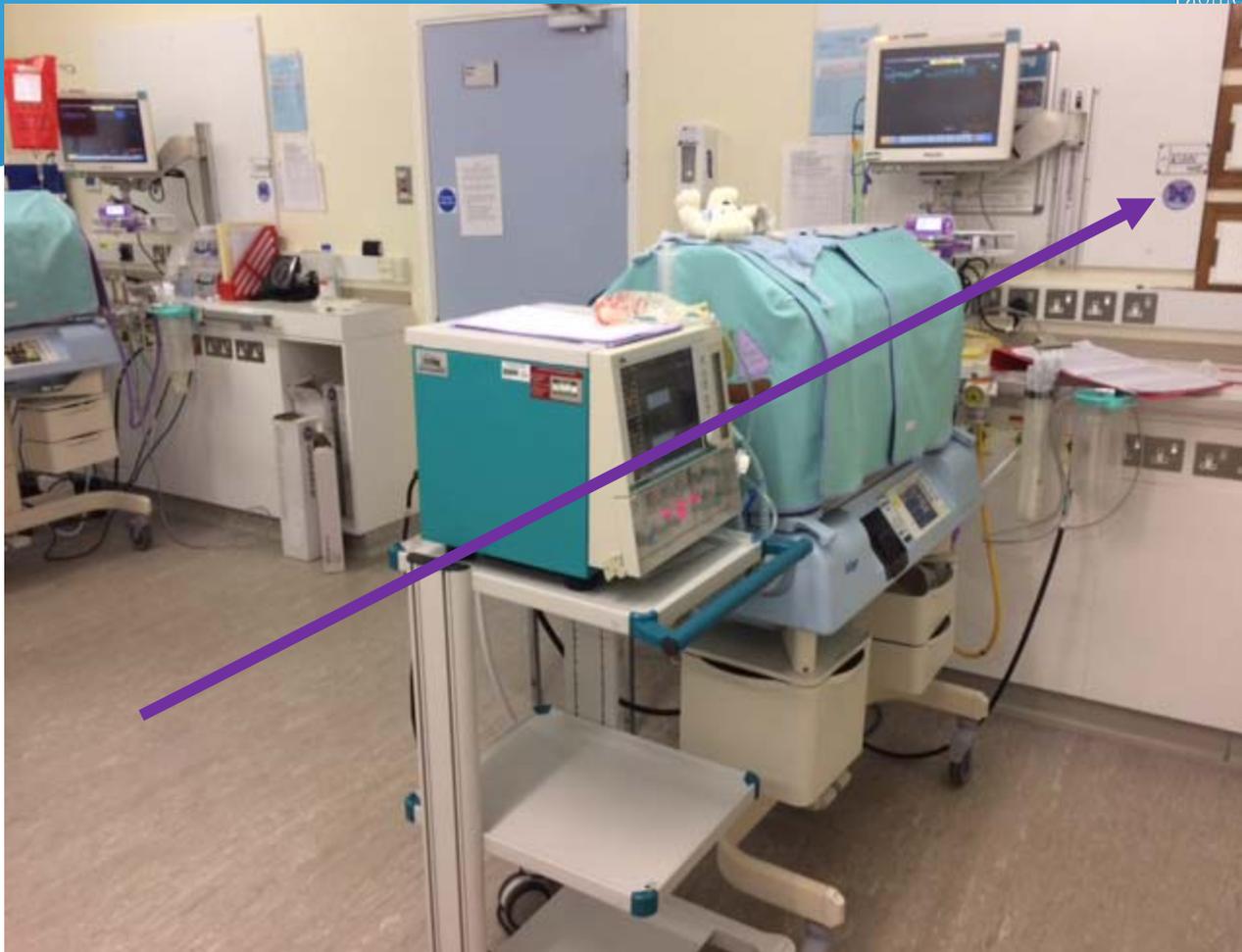
‘they forget about him being a twin [Father] ’ ‘it’s not just they forget...a lot of them did not know’ [Mother]

‘a little blue butterfly.....just put a butterfly on the cot then they know he’s a twin and then it solves the problem’ [Mother, during our workshops]



Butterfly symbol





Acknowledge the bereavement

‘one of the doctors really quite upset me and she often said to me “at least you’ve still got one”.....

*that was one of the **worst things** that anyone could possibly say’ [Mother]*



Juxtaposition of emotions

- Impact of death was underestimated
 - tendency to be positive & focus on surviving twin
 - parents value being given ‘permission’ to grieve for their loss, while celebrating their surviving baby
- Reassure parents - ‘OK’ to feel a mixed emotions
- Avoid any sense that parents are lucky to ‘still have one baby’ – **never say ‘at least you’ve still got one’**.

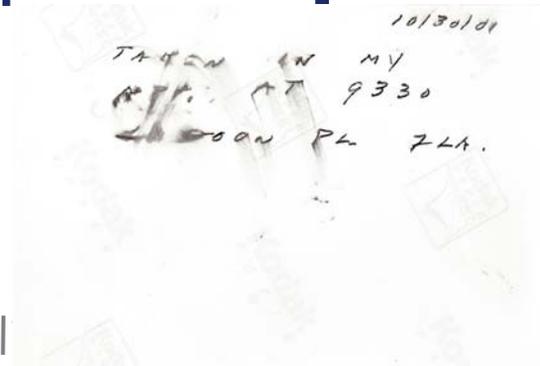
Before you tell a grieving parent be grateful for the children they have, think about which one of yours you could live without

Anon.

Provide emotional support

'it was just a bit matter of fact ('normal') to people' [Mother - referring to people helping to organise the funeral of one of her twins]

'her middle name wasn't put in and it's smudged...' [Mother – referring to the remembrance book in the hospital church]



Provide emotional support

‘one of the nurses that was least caring kept calling him [the alive twin] by his brother’s [the dead twin] name’ [Mother]



Compassion & humanity

- Many parents felt staff had become ‘like friends’
- Importance of ‘normal’ human interaction
- Parents appreciate compassion & caring – **“It’s the little things that count”**
- **Do not worry about ‘saying the wrong thing’**: any discomfort you feel is much less than the sadness the parents experience

Provide appropriate information

'we didn't know where he [the dead twin] was in the hospital. I didn't have a clue where he was' [Mother]



Provide appropriate information

- Speak with parents: help them make notes, keep a diary or provide them with written information
- Start 'memory making' with all high risk infants from the day they are born (pictures, footprints etc.)
- In-utero loss (Stillbirth): discuss what parents may want at delivery – do they want to see or hold the baby

Provide continuity

'It was really good, we knew the nurse and trusted her' [Mother]

'a lot of days it was a new nurse....we had to keep explaining it again' [Mother]



www.shutterstock.com · 429918193



Provide continuity

- Parents found it painful to retell the ‘story’
- They want the opportunity to talk about it, sometimes, but they expect that we handover to each other....
- Learn names of surviving & dead twin
- Sense of continuity – will they see you again?
 - Doctors & nurses.



Offer memory making



‘the nurses did it, they took footprints and handprints; I find it difficult to look....but I’m pleased they did’ [Mother]

‘I have got pictures....it’s nice to see that it was both of them together in the incubator’ [Mother]

‘when I look back I think “did I ever cuddle [name of dead twin]?”’ [Mother]



Handle cot occupancy sensitively

'it was not nice, putting us on a ward with parents and other twins'

[Mother]



'one thing which I did find difficultI was put next to a lot of twins' [Mother]

'it was really hard but you know it has to be done....'

[Mother – talking about a new admitted baby being put into the cot space where her dead twin had been]

Prepare parents for discharge

‘it was horrible going home when I had to come home that was really hard’ [Mother]

‘thought it would get better when I got home.... but it actually got a lot worse’ [Mother]



Prepare parents for discharge

‘it’s parents stories [written in book on NICU] they write their story...it helps me “why am I feeling the way I am?”

...they can read these stories and think “oh right these other parents are going through the same” [Mother]



Summing up

- Staff have long-term impact on parents' experience
- Small things can make a big difference
- Project is 'More than' a Butterfly sticker

- Staff: consider their own well-being
 - accept limitations and ask for help
 - strong 'informal networks' exist
 - **be aware of staff who feel more 'on the edges'**



Summary of key themes

1. **Recognise twin status**
2. **Acknowledge the bereavement**
3. **Emotional support**
4. **Appropriate information**
5. **Continuity**
6. **Memory making**
7. **Cot occupancy & NICU ‘geography’**
8. **Discharge preparation**



Butterfly project – where now?

- Guidelines, power-point slides, ‘leaflets’
- International – Spanish, French, Italian, Portuguese, Russian, Swedish, Arabic and German translations
- South and North America, NZ and Europe



Duelo por la pérdida de un embarazo gemelar

Guía para los profesionales de la salud

Spanish

Esta guía fue redactada a partir de una investigación que identificó la necesidad de orientar a los profesionales de la salud en la asistencia a los padres tras de la pérdida de un bebé después de un embarazo múltiple. Fue desarrollada en colaboración con profesionales de la salud en esta especialidad. El ánimo de esta guía es proporcionar recomendaciones sin ser obligatorias.

Si desea contribuir puede contactarse nicholas.embleton

Estas guías han si Neonatología, Hos (microbiólogo, Hos

Trauerbewältigung nach einer Zwillings-Schwangerschaft
 Leitfaden für medizinische Berufe
German

Dieser Leitfaden entstand aus einer Forschungsstudie heraus, die einen Bedarf bei medizinischen Fachkräften ermittelte, die Eltern nach dem Versterben Ihres Neugeborenen bei Zwillings- od wurde in Zusammenarbeit mit Ge: Er stellt lediglich ein

Perda na gestação gemelar
 Orientações para profissionais de saúde
Portuguese

Este guia surgiu a partir de uma pesquisa que identificou a necessidade de orientação para profissionais de saúde, a fim de que pudessem oferecer apoio aos pais após a morte de um dos bebês numa gestação múltipla. Ele foi desenvolvido em colaboração com profissionais que trabalham nesta área. Lembramos que seu objetivo é oferecer sugestões aos profissionais, para ajudá-los a lidar com o assunto. Agradecemos comentários e sugestões que possam ajudar a melhorar esse guia. Por favor envie-os para o Dr. Nicholas Embleton (Consultor em Neonatologia) nicholas.embleton@newcastle.ac.uk

Atualizações e versões em idiomas estrangeiros podem estar disponíveis em nosso site www.neonatalresearch.net/butterfly-project

Estas orientações foram desenvolvidas com o apoio de Sands (Stillbirths and Neonatal Death Charity - www.uk-sands.org) e da Fundação Múltiple Births (www.multiplebirths.org.uk) e são endossadas pela Fundação Europeia para o Cuidado de Recém-Nascidos (www.efcni.org)

Italian

Butterfly film project

- ‘Struck’ by the power of **hearing parents speak directly**
- Film project with ethnographic film maker
- 8 families, 6 NICU staff
- >60 hours of footage

Parents more than 20 years later recall what staff said and what it made them feel





The Butterfly Project

ABOUT US

HOW TO USE

THEMES & GUIDELINES (FILM)

RESOURCES

PARENTS STORIES

FEEDBACK

CONTACT US



Guideline downloads & links

The following resources are available for free download by clicking on links below:

[Butterfly_guidelines_English](#)

[Butterfly_guidelines_Spanish](#)

[Butterfly_guidelines_Francais](#)

[Butterfly_guidelines_Portuguese](#)

[Butterfly_guidelines_German](#)

[Butterfly_guidelines_Romanian](#)

[Butterfly web guideline Swedish v1](#)

[Butterfly Russian Guidelines](#)

[Butterfly_teaching_slides_for_staff](#)

[Butterfly_2_page_teaching_staff_leaflet](#)

[2-page leaflet](#)

[Butterfly_parent_leaflet_can_be_edited](#)

We developed these guidelines for use by healthcare staff in hospital settings.

These can be downloaded and added to hospital intranet sites, and used as resources in teaching and education settings. We want to acknowledge our colleagues and international collaborators who have helped to translate these guidelines into other languages. We are keen to make these resources as widely

RESOURCES

[Guideline downloads & links](#)



The Butterfly Project

- ABOUT US
- HOW TO USE
- THEMES & GUIDELINES (FILM)
- RESOURCES
- PARENTS STORIES
- FEEDBACK
- CONTACT US
- Q

Special status



1. Feeling special about having twins



2. When parents lose a twin baby



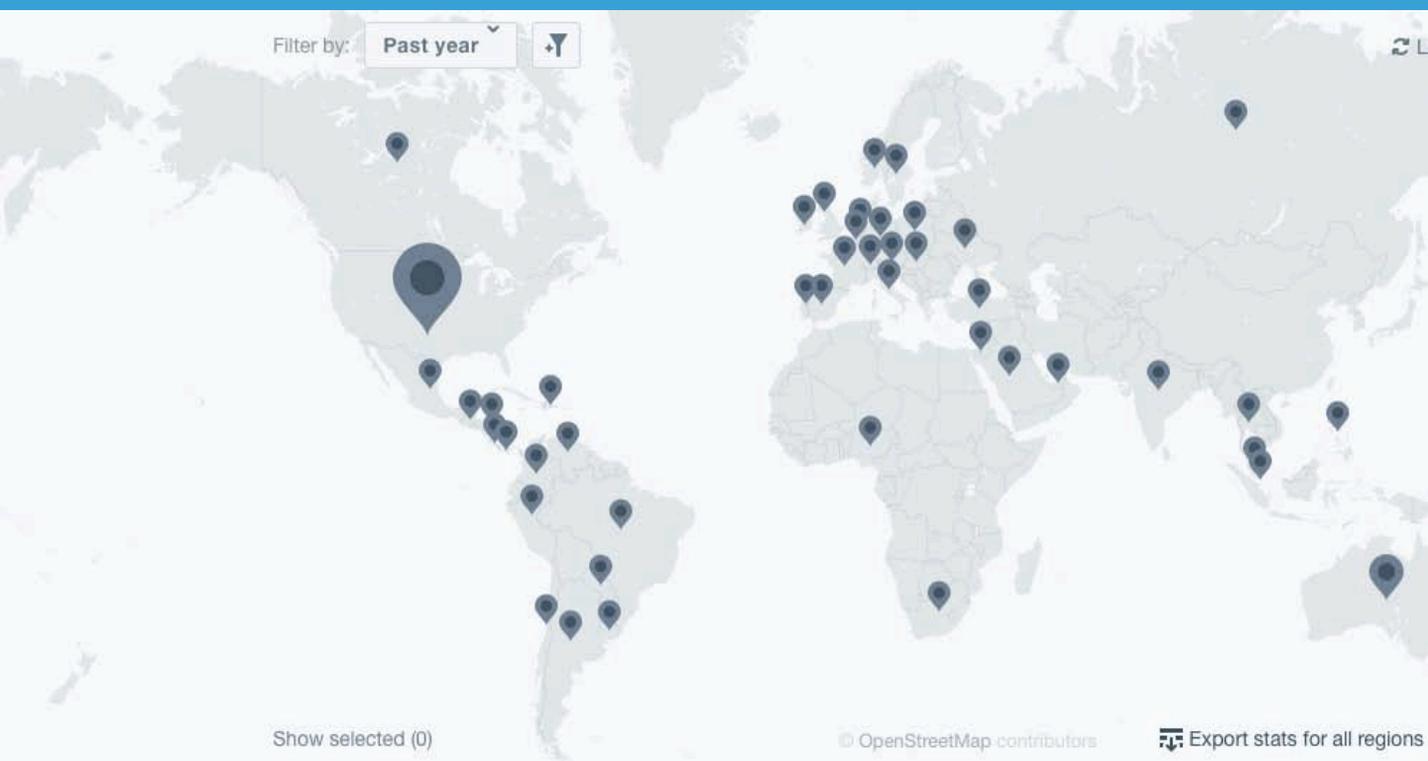
3. Acknowledging bereavement and twin-ship

Trust & understanding



Filter by:

Past year



Show selected (0)

© OpenStreetMap contributors

Export stats for all regions

Region <input type="radio"/>	Plays	Finishes	Impressions
United States	6962	816	176486
United Kingdom	1739	415	35827
Australia	1689	235	46849

Butterfly project North East

Secret group

About

Discussion

Members

Events

Photos

Moderate group

Search this group

Shortcuts

- Butterfly project North ...
- Neonatal Research 2
- FORO DE NEONAT... 20+
- www.neonatalresea... 11
- GOLD Perinatal Con... 8
- Unicef UK Baby Fri... 14
- FORO DE PEDIAT... 20+
- Junior Doctors Co... 20+
- 61st Newcastle Sco... 2

Photo/Video Get together Poll

NEW ACTIVITY



Nadia Leake
8 hrs

Working in my office and found this on the floor... thought of you. Hope you're all having a lovely day ❤️



SUGGESTED MEMBERS

Friends

- Sasha Stephenson [Add Member](#)
- Lizzie Worrall [Add Member](#)
- Chloe Rolls [Add Member](#)

See More

DESCRIPTION

A closed group for families in the North East who suffered the loss of at least one baby from a multiple pregnancy.

LOCATION

Add locations for this group.

TAGS

Add a few descriptive keywords.

CREATE NEW GROUPS

Groups make it easier than ever to share with friends, family and teammates.

[Create Group](#)

RECENT GROUP PHOTOS



Suggested Groups

Chat (40)





The Butterfly Project: how can staff improve the experiences of parents who suffer the loss of a baby from a twin pregnancy?



Good research is a team effort

Parents, families, siblings and staff

International translators

Newcastle University

Judy Richards, Louise Hayes, Lisa Crowe, Ruth Graham, Judith Rankin

Newcastle Hospitals NHS Foundation Trust

Sarah Stephenson, Nicholas Embleton, Clare Campbell, Jane Couch, Janet Berrington

Multiple Births Foundation

Jane Denton

Film Producer

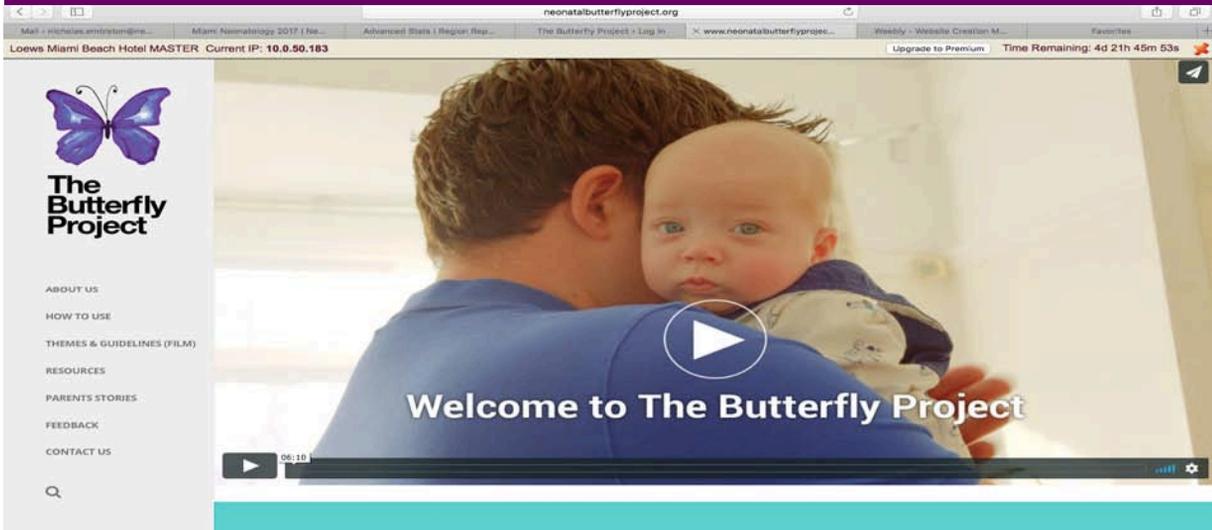
Reuben Abrahams

Butterfly project – a work in progress



Indebted to parents who felt able to share their experiences with us

www.neonatalbutterflyproject.org



The screenshot shows a web browser displaying the Neonatal Butterfly Project website. The browser's address bar shows the URL www.neonatalbutterflyproject.org. The website features a purple header with the URL, a navigation menu on the left with links like 'ABOUT US', 'HOW TO USE', and 'RESOURCES', and a central video player. The video player shows a man in a blue shirt holding a baby, with the text 'Welcome to The Butterfly Project' overlaid. The video player controls show a play button and a progress bar at 00:10. The browser's status bar at the bottom indicates 'Loews Miami Beach Hotel MASTER' and 'Current IP: 10.0.50.183'.

Films with parents who suffered loss of a co-twin baby
Free to download guidelines, translations, resources,
teaching packs

Sophie 24weeks 550g - born on my birthday1996!
I was the neonatal fellow (but I was not at work)
Twin sister Beth died on day 1 – I didn't know until 2015
Grade AAA nursing student - now works on my NICU!

