

The British Intestinal Failure Survey

A Registry to Record Incidence and Outcome of Childhood Intestinal Failure

Newsletter No. 1 - January 2009

Welcome to the first BIFS newsletter. It's aims are to give regular feedback on how the registry is progressing, and to provide an open forum for ideas or innovations to be shared.

The aims of BIFS

Intestinal failure refers to the reduction in function of the gastro-intestinal tract to the point where it can no longer support normal growth. While there have been a number of studies of children with intestinal failure carried out within individual trusts, there remains a lack of current data on the situation country-wide.

The British Intestinal Failure Survey is a national registry commissioned by the British Society of Paediatric Gastroenterology, Hepatology and Nutrition, (BSPGHAN) the British Association of Paediatric Surgeons (BAPS) and the Department of Health through the National Commissioning Group (NCG), and its aim is to determine the incidence and outcome of intestinal failure in children in the UK and to quantify the number of children who may progress to require intestinal transplantation. It should be noted that the commissioners retain ownership of the data.

Children 18 years of age or under when they start PN who remain on PN for more than 27 days are eligible to be recruited into BIFS. Pre-term neonates on PN because of immature GI function are excluded.

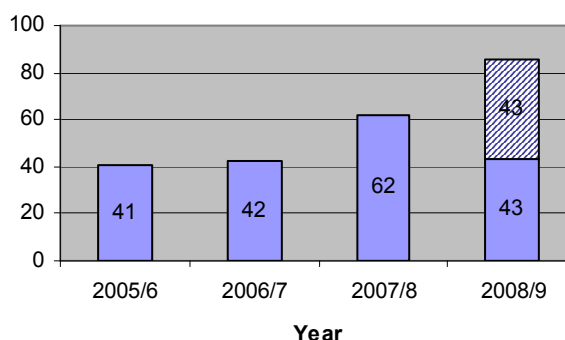
Hospitals that wish to submit data will however have to obtain approval from their own R&D Department.

Registration of patients depends on their parents or guardians signing a consent form, and to assist them a series of patient information leaflets have been produced.

BIFS progress so far

BIFS registered its first subject in July 2005. Since then it has grown and as of the end of 2008 has recruited 188 subjects from ten contributing centres. Graph 1 shows recruitment has increased year on year, and I am hoping that by the end of June 2009 we should have recruited about 230 subjects.

Graph 1. Registrations per year (July - June)



For more information or to get involved, contact:

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Centre involvement

BIFS continuing success depends on ensuring that all trusts that provide paediatric PN are involved, and that they try to recruit all eligible patients. Involving a new centre to start recruiting patients therefore involves:

1. Identifying centres and staff that are willing to carry out the work
2. Obtaining Trust Research and Development Department approval
3. Recruiting patients, and
4. Following up recruited patients every six months.

The Pharmacy PN Database

All of this would require a lot of additional work from health professionals at trusts throughout the UK. Having noticed that all of the data required by BIFS was routinely being collected on all patients on PN anyway, I set about developing a database that could be used by pharmacy departments that would centralise information needed for BIFS, but would more importantly be used as a tool by the trusts themselves to record PN data. This information would be available exclusively to the trust and could be used for meetings, audits, discharge summaries and so on.

The pharmacy database alerts the operator which patients should be approached for recruitment into the BIFS study, calculated from how long they have been on PN. It also enables a summary of the data on patients who have agreed to participate in BIFS to be sent directly to the BIFS registry office in the form of a spreadsheet. The data can be sent via the NHS.NET e-mail system as this has the level of security required by the BMA.

Use of the PN database should go some way to reducing the amount of additional work that submitting data to BIFS would require by reducing the amount of duplication and repetition currently involved.

Contributing centres

Leeds
Bart's and the London
Birmingham
King's College Hospital
Liverpool
Sheffield
Norfolk & Norwich
Royal Free Hospital
St George's, London
Cardiff

R&D Approved Centres

GOSH
Dublin
Nottingham
Doncaster
Bristol
Manchester
Lewisham
Sunderland
Edinburgh
Chelsea and Westminster
Addenbrooke's Hospital
Yorkhill Hospital, Glasgow
Leicester
Newcastle

R&D Approval Ongoing

Southampton
Belfast *
Oxford *
Hull *

* Early contact stage

I have always depended on the kindness of strangers