

IBD



SUPPORT
AUSTRALIA



**IBD SUPPORT AUSTRALIA
INCORPORATED**

2013 Annual Report



**NOTICE IS HEREBY GIVEN THAT THE ANNUAL GENERAL MEETING
OF
IBD SUPPORT AUSTRALIA INC
WILL BE HELD AT 8PM WEDNESDAY 27TH NOVEMBER 2013
ONLINE VIA MUMBLE¹**

As part of the AGM, a new Committee will be appointed. Please complete a nomination form prior to the meeting taking place via <https://www.ibdsupport.org.au/members/agma> to nominate your preferred position on the committee (if any). Nominees will need someone to second their nomination. If you are unsure of who to ask as a 'second', please contact a current committee member.

The agenda for the meeting is as follows:-

1. Opening and Welcome
2. Attendance
3. Apologies
4. Receive and adopt the Annual Report
5. Receive and adopt the financial statements
6. Election of office bearers for 2014
7. To deal with any Notices of Motion received by the Secretary
8. Correspondence & Accounts for payment
9. General business (immediate and urgent only)

Notices of Motion are to reach the Secretary by 12 noon, 13th November 2013

By order of the Committee

*We provide online support and resources for people
with Inflammatory Bowel Diseases including
Crohn's Disease and Ulcerative Colitis.*



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AMY, DIAGNOSED IN 2001

"The beauty of a local site is that you use the same words and medication and you can meet each other in person. When you are going through a bad patch you can post and write a message and people will get back to you and give you support. That was really nice to feel like I wasn't going through that alone."





PRESIDENT'S REPORT

The 2013 Committee

The following people were elected as our committee, which has been responsible for the management of the Association and also the website at www.ibdsupport.org.au

President - Katherine Stewart (Kate59)

Secretary - Joanne N (Jo1980)

Treasurer - Claudine D (Claudine)

Ordinary Committee Members - Stefan N (stefan) and Carly C (charliegirl b)

Due to a lack of nominations, the executive committee only had 3 of a possible 6 positions filled.

I would like to take this opportunity to thank everyone on the committee for their efforts in helping each other and filling gaps as was necessary to complete our second year of incorporation and the running of the newly updated website.

Our History

The forum was started on 13th September 2003 with a mere handful of users, and by the end of the 2013 financial year had 1116 registered users. The website was initiated by a young lady with Crohn's Disease when she realised there was very little information freely available about Crohn's and Colitis specific to Australia. Since 2003, the website has undergone several redevelopments and enhancements, both of administrative and technical natures.

With the forum community recently forming as a non-profit incorporated association to ensure the long term viability of this community, we are ensuring it can continue to support those with Inflammatory Bowel Disease (IBD), whilst remaining free to users. However, because we are an incorporated association we need to have members to our association who have to meet a criteria as set out in our Constitution and pay an annual fee. Association members elect the committee every year, and are able to nominate for positions on the committee themselves. The association must continue to increase paid membership to enable future projects and to remain financially viable. While we can receive sponsorship or grants for individual projects, in compliance with section 42 of the constitution, we are unable to receive funding for day to day running costs of our association, so still rely on the membership fees and donations to allow us to keep operating.

Achievements Related to Constitutional Objectives

Our second year as an association was demanding for the committee, with a small committee, and many of us having personal challenges, often involving our health. We have tried to continue to run our association to the best of our abilities and available free time. The following is an outline of how we feel we have met our objectives:

To provide a support network for patients with inflammatory bowel disease and their families; through an online forum and other online resources.

Our website usage statistics in the following section reflect how much our site is being utilised and by whom, and demonstrate that we are still providing a website that people find useful. We also operate a secret Facebook group which maintains people's privacy unlike most other open or closed groups on Facebook. Regular forum users are able to join our Facebook group, and it attracts a significant amount of activity, but it is not included in our statistics.

We also continue to advertise any Australian IBD meetings and support groups on our website as we are made aware of them, or requested by facilitators. We have been communicating with Crohn's and Colitis Australia (CCA) to promote more of their events in future.

To exchange experiences and knowledge of how others cope with their disease in everyday life.

Although we have not had as much traffic to the site this year, we were still being found by new users, as demonstrated in the website statistics in the following section. We have had a total of 105 new registered users this financial year, who collectively made a total of 406 posts, or an average of 3.9 posts each. There were a total of 2688 posts made during this financial year, or 7.4 posts per day, and our website had a total of 170,754 page views, or 468 per day, down 35.5% from 264,759 the previous year.

To advocate for better access to treatment options for those with inflammatory bowel disease.

We have continued to develop a process to allow the promotion of clinical trials and research projects available into IBD related issues being available on the site. We have had several such projects advertised on our site this year, some of these include:

- + Results were made available from the "Study on Antidepressants Use in IBD" by Dr Antonina Mikocka-Walus and Dr Jane Andrews which many of our users participated in last financial year
- + IBD Clinic at www.ibdclinic.org is a psychological assessment developed by Dr Simon Knowles, and provides a 14 week online psychologically focused treatment program that is available free of charge
- + A clinical trial for Osiris (Mesenchymal stem cells) to treat Crohn's Disease, available for those with active disease, previously treated with either Infliximab or Humira, at both the Royal Adelaide Hospital and the Royal Melbourne Hospitals.

***To be a not for profit association and be able to obtain funds
or in kind sponsorship to help us provide free and valuable support
to users and members.***

The website and our association are funded by membership fees, donations we receive to the website either directly or through Give Now¹, as well as by committee members providing consultancy services. A big thank you to those who have become members throughout the year and those who have donated money towards our ongoing work.

AbbVie has continued to support us by providing us with funding to design, print and distribute our new business cards and flyers. They also provided us with an educational grant for 2 of our members to attend Australian Gastroenterology Week (AGW 2013) which was held in October, 2013. AGW 2013 will be covered in more detail later in this report.

***To work alongside other like-minded persons
and organisations to achieve these goals.***

The committee has worked with several organisations during the past financial year, and intend to continue to expand this through events such as AGW 2013. This has included:

- + Attendance at an Australian IBD Working Party meeting to assist in identifying gaps in IBD care and development of survey into some of the issues of living with IBD, eg maintaining relationships and employment during flares. This included gastroenterology specialist physicians involved in IBD, Crohn's & Colitis Australia (CCA), consumers, pharmacists, psychologists and a representative from IBD Support Australia Inc
- + Involvement in the development of a Parenteral Nutrition Brochure with Parenteral Nutrition Down Under, with the Agency for Clinical Innovation (ACI). *See Appendix 1*
- + Meeting with Francesca Manglaviti, Chief Executive Officer of Crohn's & Colitis Australia after AGW 2013

IBD Support Australia is run by a committee of volunteers.

¹ <http://www.ibdsupport.org.au/help-us>

Website Usage Statistics

Our data was collected using Google Analytics, and in accordance with our Privacy Policy, none of the data used within this report identifies any individuals. Note that the years referenced in all graphs relate to the financial year ending.

As previously stated our number of visitors was down this year by 9834, and some of this decrease may be attributed to the many easily accessible Facebook pages for IBD, which may be attracting some of our users. Unfortunately many users are unaware these Facebook pages often offer little or no privacy, which remains of concern to the committee.

Thousands of Visitors by Financial Year

This financial year the number of visits was down from 46,702 to 36,668, a drop of 21%, however we had 14,314 unique visitors to our website, an increase from 13,062 of 9.6% from last year. We also had 170,754 page views, down 35% from 264,759 from last year.

We have maintained a steady increase in both new and unique visitors, suggesting that people may not find the need to keep returning to our site for continued support as much as previously.



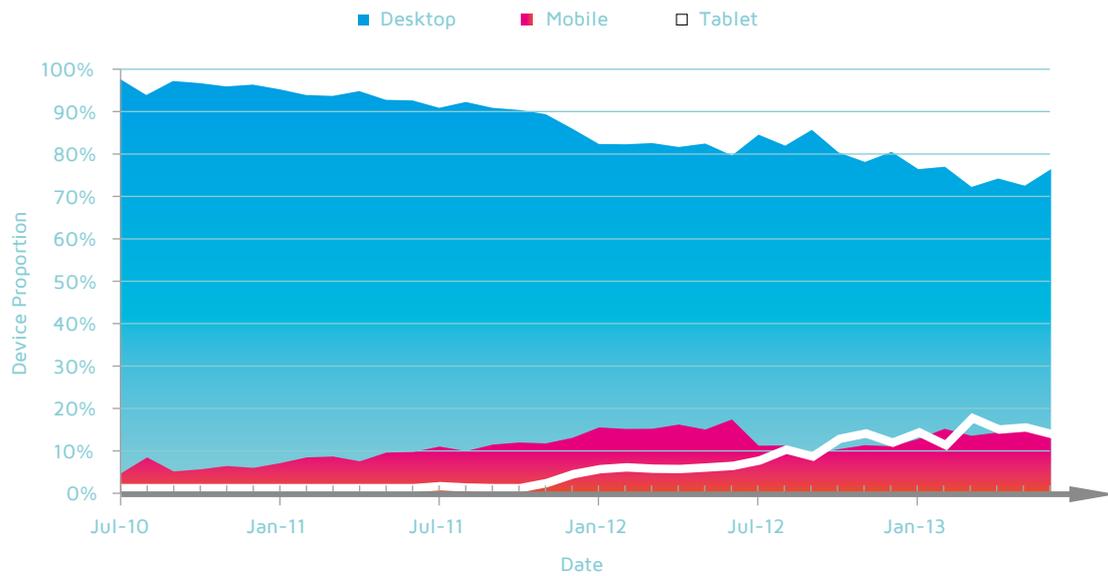
Visits by Country

Financial Year 2012/2013

Our website continues to attract visitors from a wide range of countries, though the Australian traffic continues to be the vast majority at 80.9%. This year a total of 93 countries were represented, with the United States, United Kingdom, Poland and New Zealand each comprising of more than 1% of the total traffic.

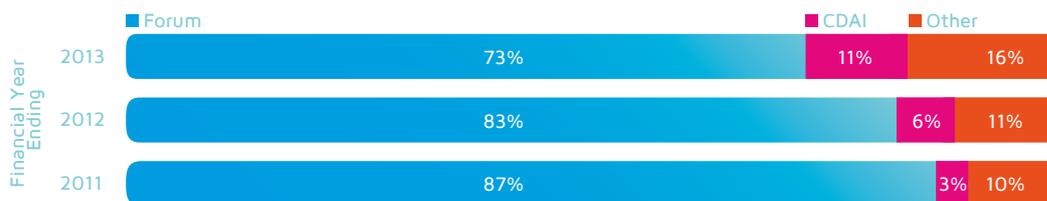
Devices by Unique Visitors

The increasing trend of mobile and tablet devices has continued to increase this financial year, though not as drastically as past years.



Content by Page Views

Our Crohn’s Disease Activity Index (CDAI) calculator continues to generate significant amounts of traffic, as it remains ranked very highly on search engines for those looking for information on CDAI. Wikipedia also links to our CDAI calculator.



Attendance at Australian Gastroenterology Week (AGW) 2013

The committee investigated having multiple attendees representing the association for AGW 2013 in Melbourne and successfully received an educational grant from AbbVie for 2 committee members to attend this year's conference in addition to the free of charge attendee and association counter provided by the AGW committee, which was shared between 3 of our users who were based in Melbourne. The report from AGW will be in next year's Annual Report as it was held in October 2013.

Promotion of Research & Clinical Trials

The committee continues to receive requests from health professionals as well as both institutional and industry representatives for advertising for IBD related studies and clinical trials. These are reviewed by the committee to ensure a benefit to the participants or wider IBD community.

With a large number of new contacts obtained during AGW 2013, it is likely that we will receive more requests in the coming year.

As an association we will continue to advertise relevant clinical trials and research as it not only helps advance understanding of IBD and new treatments among health professionals, but also helps provide access to upcoming treatments for our forum users.

Industry Consulting

Some committee members have been involved in consultancy work over the past year, with all proceeds being paid to the association.

This has included a major study in the issues for people living with IBD, which typically get very little coverage in other studies. This study took the form of a survey which collected insights on the emotional and mental health impacts of IBD in Australia.

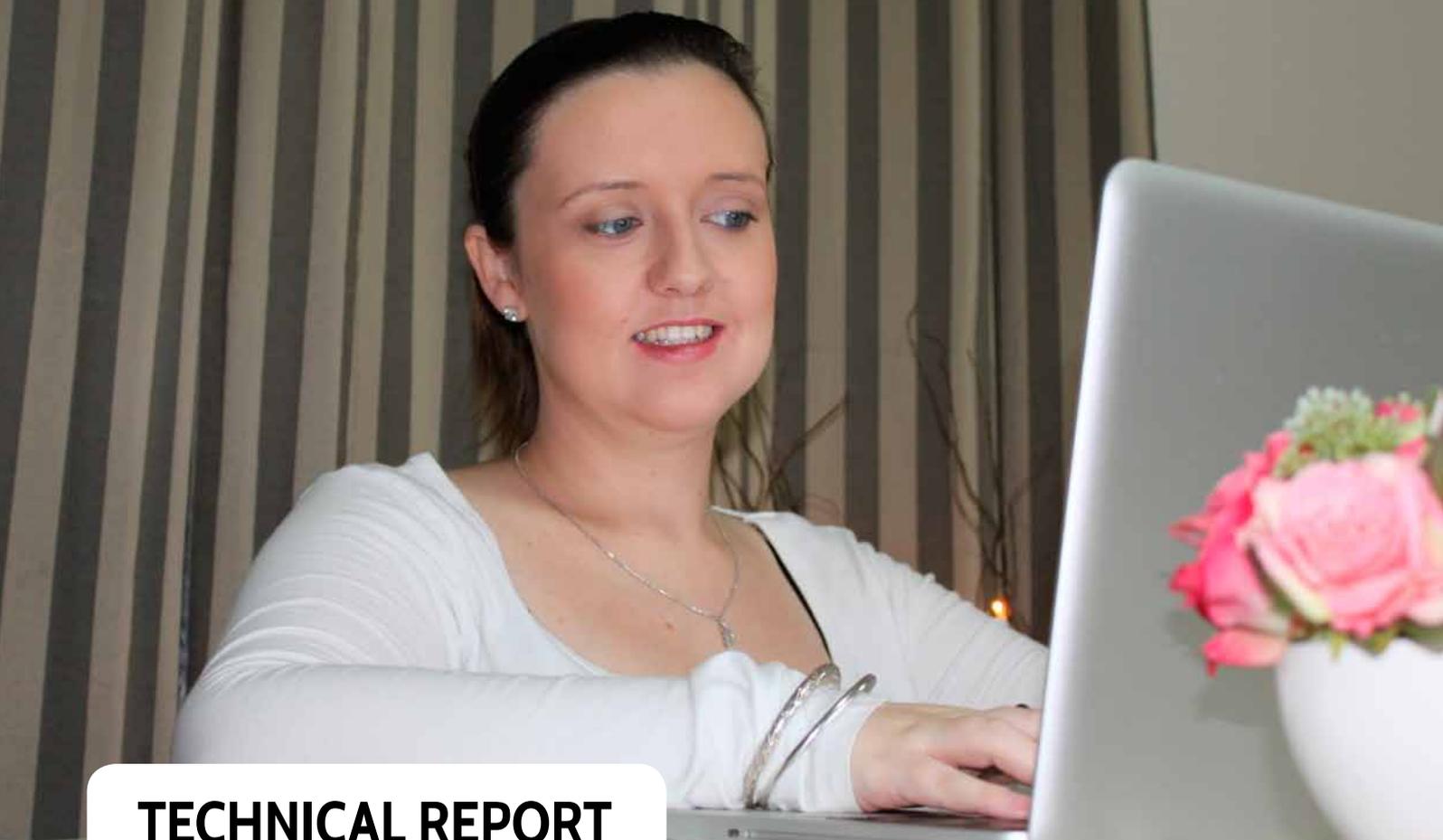
Another study of interest we have consulted on has been a Pharmaceutical Industry Interaction Study by IMS Health, aimed to better understand the interactions between health consumer organisations such as ourselves and pharmaceutical companies.

While some of this consultation took place during the 2013 financial year, payment for this will not appear until the 2014 financial summary.

JO, DIAGNOSED IN 2004

"Living with IBD has been challenging at times but thanks to the support of the IBD Support Australia community, I have a group of friends who can help me in my time of need. I am forever grateful to the forum and will always be a part of the IBD online family!"





TECHNICAL REPORT

The past year has involved very few changes of a technical nature, other than regular software updates. We have started to utilise some new Amazon Web Services (AWS) products to provide an automated response to redirect traffic in the event of an outage, at minimal extra cost. This will minimise any observed downtime to be at most a couple of minutes in the event of an outage, which has helped us achieve an estimated uptime of at least 99.90%, or at most 8 hours of downtime, assuming a worst case scenario from our limited reporting data.

We believe we are now on track with our high availability goals, though with the number of systems involved this is hard to measure, and not necessarily reflected by the free reporting tools available to us which assume a 5 minute outage where our systems should respond and redirect traffic with in 1 minute.

Our goal is to inspire and support through the exchange of ideas, experience and morale.

FINANCIAL SUMMARY

The following is the Balance Sheet & Cash Summary for the financial year ending June 2013.

These reports have been generated using Xero Accounting.

Balance Sheet

(as at 30 June 2013)

	30 Jun 2013	30 Jun 2012
Assets		
BANK		
Cash Reserve	\$126.49	\$51.48
CTO Debit Card	\$75.33	\$77.34
Executive Debit Card	\$0.00	\$7.01
PayPal	\$0.00	\$86.94
Transaction Account	\$0.00	\$399.99
Total Bank	\$201.82	\$622.76
CURRENT ASSETS		
Accounts Receivable	\$400.00	\$0.00
Total Current Assets	\$400.00	\$0.00
Total Assets	\$601.82	\$622.76
Liabilities		
CURRENT LIABILITIES		
Accounts Payable	\$969.05	\$0.00
GST	-\$84.21	-\$14.92
Rounding	-\$0.01	\$0.00
Total Current Liabilities	\$884.83	-\$14.92
Total Liabilities	\$884.83	-\$14.92
Net Assets	-\$283.01	\$637.68
Equity		
Current Year Earnings	-\$920.69	\$9.44
Retained Earnings	\$637.68	\$628.24
Total Equity	-\$283.01	\$637.68

Cash Summary

(For the 12 months ending 30 June 2013, ex. GST)

	30 Jun 2013	30 Jun 2012
Income		
Donations General	\$135.00	\$0.00
Donations Give Now	\$180.00	\$120.00
Grant for Conferences or Education	\$4,800.00	\$0.00
Interest Income	\$26.38	\$6.39
Membership	\$40.00	\$40.00
Other Revenue	\$0.00	\$125.00
Total Income	\$5,181.38	\$291.39
Less Operating Expenses		
Bank Fees	\$1.89	\$0.13
Consulting & Accounting	\$291.78	\$0.00
Freight & Courier	\$0.55	\$0.00
General Expenses	\$330.55	\$128.85
Merchant Fees	\$1.63	\$1.09
PayPal Fees	\$3.06	\$3.06
Printing & Stationery	\$4,360.00	\$0.00
Website Expenses	\$595.54	\$148.82
Rounding	\$0.01	\$0.00
Total Operating Expenses	\$5,585.01	\$281.95
Operating Surplus (Deficit)	\$-403.63	\$9.44
GST Movements		
GST Inputs	\$-528.31	\$-14.92
GST Outputs	\$511.00	\$0.00
Net GST Movements	\$-17.31	\$-14.92
Net Cash Movement	\$-420.94	\$-5.48
Summary		
Opening Balance	\$622.76	\$628.24
Plus Net Cash Movement	\$-420.94	\$-5.48
Closing Balance	\$201.82	\$622.76



LOOKING FORWARD

Some of the following issues we are still exploring or are on our wish list for 2014.

- + Funding for search engine optimisation (SEO) has been delayed due to other priorities, which will also lead to improving our targeted online advertising.
- + The committee has begun investigating opportunities to improve the functionality and accessibility of the CDAI calculator, and hope to begin work on this project in the New Year.
- + Again request an educational grant to allow several members to attend Australian Gastroenterology Week 2014 in the Gold Coast.
- + Explore options with Crohn's and Colitis Australia (CCA) about working together in projects that raise awareness and also raise money for IBD research.
- + Work more closely with likeminded organisations, especially CCA, to achieve our objectives, including projects to raise awareness, as well as funds for IBD related research.
- + Continue to increase our membership base to ensure the association can continue to function. This will also allow for more people to become involved in the running of the association.

Our goal is to inspire and support through the exchange of ideas, experience and morale.

Parenteral Nutrition

An Information Guide for Patients and Carers

You have been referred for Parenteral Nutrition (PN). This factsheet will help you to understand what this is and how it may affect you.

What is Parenteral Nutrition (PN) and why is it needed?

When you eat, food passes from the stomach into the digestive tract (also known as the bowel or gut), where it is broken down and absorbed into the body. However, you may not be able to digest food in the normal way. There might be various reasons for this and you can discuss this with your medical team.

When your digestive tract is not working, you still need nutrition. This is when you need PN (sometimes called Total Parenteral Nutrition or TPN).

PN is a sterile solution containing nutrients normally found in food – protein, carbohydrate, fat, water, vitamins, minerals and electrolytes. The solution is infused straight into the bloodstream, bypassing the digestive tract.

You will need PN until the digestive tract is working properly (absorbing nutrients). Just like eating and drinking after any illness, improving your nutritional state takes time. This may include slow weight gain, if required.

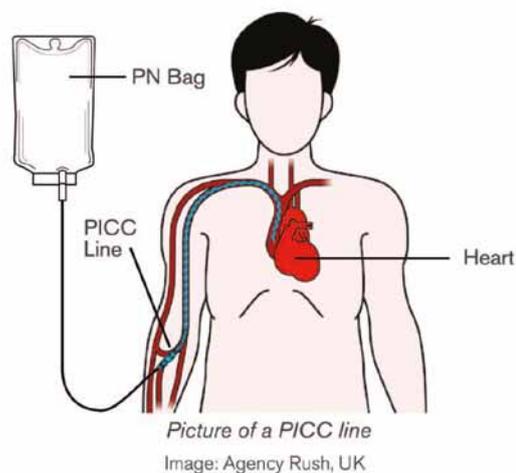
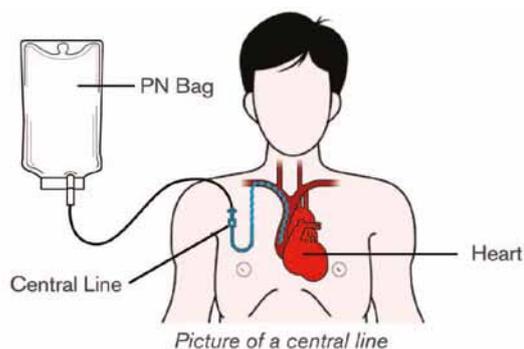
How does it work?

PN is given via a drip (intravenous infusion) into the bloodstream using an infusion pump. PN is a concentrated solution so it must be given into a large (central) vein. Medical and nursing staff will often use the terms 'line', 'catheter', 'device' or 'port'.

Your medical team will discuss the most suitable type of device/catheter and way of accessing this large vein when obtaining your consent.

ISSUE DATE: JUNE 2013

The pictures below are two examples of how PN can be given - via a "central" line or a "PICC" line (a peripherally inserted central catheter).



PN is usually infused continuously over 24 hours. The PN bag is changed about the same time each day.

What will happen while on PN?

During your PN therapy you will be monitored closely. This will include regular blood tests, temperature, pulse and weight checks. Nursing staff will care for your catheter on a regular basis. It is very important to keep the catheter clean.

This helps to reduce the risk of infection. Hand hygiene must be maintained at all times.

Tell the nursing staff and medical team immediately about any of the following:

- painful or uncomfortable catheter site,
- a leaking catheter,
- fever, shakes, shivers or sweats.

Frequently Asked Questions

Will I feel hungry or thirsty?

On PN, you may not feel hungry or thirsty at all. This is because you are receiving all of the nutrition you need. If you are feeling hungry or thirsty, talk to your medical team.

Can I eat and drink?

This depends on your medical condition. This will be explained by your medical team.

Oral hygiene/mouth care

Good mouth care is important even when you're not eating or drinking. Cleaning your teeth and/or having regular mouth washes will help with oral hygiene. If your mouth is dry, tell your medical team.

Will I still need to go to the toilet?

Yes. Your bladder should work normally. The bowel still produces secretions if you are not eating.

What happens if my dressing is loose or coming off?

The catheter site must remain clean and dry. If the dressing is wet, loose or soiled tell your nurse immediately.

Can I shower?

Yes. Your catheter site and dressing must be kept dry in the shower. Baths are recommended for children. If your catheter site or dressing becomes wet, tell your nurse immediately.

Benefits and risks

The medical team will discuss the benefits and potential risks of PN with you.

If you have any other questions please speak to a member of your medical team.

Glossary of Terms

Catheter (Intravenous): a tube that can be inserted into a vein to give medications or fluids straight into the bloodstream.

Digestive tract/Gastrointestinal tract (sometimes called 'gut'): all the organs that break down food and absorb the nutrients that are used by the body for fuel. The organs of the digestive tract are the mouth, oesophagus, stomach, small and large bowel (intestine), rectum and anus.

Intravenous Infusion: a method of giving drugs and/or fluids continuously, through a needle or catheter inserted into a vein.



This information sheet was developed by the ACI Gastroenterology and Nutrition Networks, Parenteral Nutrition Down Under and IBD Support Australia Inc.



Parenteral Nutrition Down Under
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