

- Self-Injecting brings freedom for patients
- Allows for a more flexible treatment regime.
- Essential to be instructed on how to self-inject by a medical professional.

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## More Patients Learn to Self-Inject.

Many members of the society have been requesting information about how to go about self-injecting, and the society has produced a fact-sheet on the practice that has been written by member and self-inject enthusiast Suzi Kennefick.

"I'm self-employed and found it both costly and time-wasting to keep going to my doctor's surgery once a month for a 5 minute visit. My sister, who is a nurse, suggested that I could be taught to self-inject and so I decided to investigate this. My GP was agreeable - the rest is history" says the mother of four who lives in Ireland.

The injection of either Hy-

droxocobalamin or Cyanocobalamin is intramuscular which means it has to be injected into a muscle and so it's important



**Self-inject enthusiast  
Suzi Kennefick**

that anyone who is thinking about administering their own medication first of all talks it over with his or her doctor and then receives tuition on injecting technique from a medical

professional.

"Before embarking on self-injection it is vital that you are shown how to do this by a medical professional" says Suzi. "They should give you a tutorial and will probably send you home with some needles to practice on oranges. Once you are confident and have done at least one self-injection in front of a medical professional you should be ready to proceed. Good luck to all who try self-injecting, it is easy once you've been taught how to do it and it gives freedom around your treatment".

The Self-Inject factsheet is now available from the society. Contact details on the back page.

## Genetic Research Into P.A. Begins

This month sees the beginning of the research being undertaken by Dr. Bill Newman of The Department of Medical Genetics, St. Mary's Hospital, Manchester, in the U.K..

In a unique collaboration with the Pernicious Anaemia Society Dr. Newman hopes to discover the relationship between PA.

and other auto-immune diseases such as Psoriasis, Thyroid disease, Rosacea, Tinnitus and Arthritis. And the research, which involves analyzing blood or mouth swabs, will also explain the inherited aspects of Pernicious Anaemia.

Shocked by "the paucity of research into P.A.", Dr. Newman

is hopeful that the results of the study will rekindle interest by medical professionals in P.A. and lead to a better understanding of the condition.

*If you would like to participate in the study please contact Dr. Newman on*

*01612 766264. Non U.K. Members should contact:*

*chair@pernicious-anaemia-society.org*

# Juvenile Pernicious Anaemia

## Juvenile Pernicious Anaemia

was first reported in 1937 but a diagnosis is often overlooked due to the patient's age. There are many reasons for Juvenile Pernicious Anaemia to develop in children and most are related to a hereditary factor involving the intrinsic factor. It can affect children from the age of newborn infants right up into the twenties.

JJ, a 13 year old boy was recently diagnosed with sub-acute

combined degeneration of the spinal cord secondary to pernicious anaemia.

He had been ill since January of this year but because of his age, a B12 deficiency was never considered. At the insistence of his paediatrician, JJ was referred to a haematologist at the Sick Children's Hospital in Toronto but before he could keep the appointment he collapsed.

Arrangements were quickly made to have him admitted to the hospital where it took the

haematologist only ten minutes to diagnose a B12 deficiency. Later tests confirmed PA and a later test confirmed SACDSC.

If your child displays symptoms of lethargy, dyspepsia, decreasing exercise tolerance, mood swings, depression, loss of appetite, pallor, particularly if there is a yellow tinge, get his/her b12 level checked. You could just possibly be saving your child's life.



Rare and difficult to diagnose—Juvenile Pernicious Anaemia sufferer JJ with gifts from the society.

*"Identifying the culprits must have been relatively easy"*

## P.A. Society's Bank Account Raided

£780 was taken from the society's bank account in August using a scam not encountered by the Natwest Bank or the police.

The fraudsters had managed to set up three Direct Debits using the society's sort code and account number. These debits were used to purchase insurance for two cars and annual house insurance.

When the Direct Debits were discovered they were immediately cancelled by the bank and the Fraud Department within the bank were notified. South Wales Police were also informed but, as the bank assured the society that the money would be re-imbursed, it was the bank and not the society that would need to liaise with the investigating

police officers.

How the fraudsters actually managed to withdraw any money from the activity is a mystery. And because the debits were made to insure the cars and house. Identifying the culprits must have been relatively easy.

The society has had all the money re-imbursed.

## NEW POSTERS WILL RAISE AWARENESS OF THE SOCIETY.

More and more sufferers of Pernicious Anaemia are becoming aware of how the society can help them to understand and manage their condition. However, there are still a great

disease who are unaware of the society's existence.

In order to raise awareness of the society amongst both patients and medical professionals the society now has available posters in various sizes which can be used to inform people of its role in

supporting and informing sufferers and their families.

If you can think of somewhere that might be a suitable place to advertise our existence please contact us so that we can forward some posters to you. They are available in A3 and A4 sizes.

Posters have now been produced to raise awareness of the society.



## PA COLLECTION BOX FINDS HOME IN FIFTH WHEEL

**Fifth Wheel Truck Stops** are to be found scattered across Canada and are



popular not only with truckers, but also with families seeking value for money and wholesome food.

Situated in Bowmanville, Ontario, the Fifth Wheel Truck Stop is owned by franchisee Mark Allott who began working for the truck-stop chain at the age of sixteen.

And it is at the Bowmanville Fifth Wheel

where you can find the society's most lucrative box. Situated at the cash register in the ever-popular restaurant the Bowmanville Collection Box yields more donations than any other box in the world. And donations come not just from truckers but from other users of the restaurant.

**Owner/Franchisee of the Bowmanville Fifth Wheel—Mark Allott with his certificate of appreciation.**

"Only about 40 per cent of our customers are truck drivers, the other 60 per cent is comprised of tourists and ordinary travellers" explained Mark. "Many people who donate to the box have never heard of Pernicious Anaemia and so Pat wrote an explanation that donators can read and understand the condition."

With a roster of 80 employees, Mark is kept busy running a large business that not only includes the restaurant

but a gift shop, a gas bar and a motel.

Mark immigrated to Canada from his native Sheffield, England, in 1966. He still finds time to go back to visit relatives in Sheffield and will probably be crossing the Atlantic next year.

In recognition of the generosity of the customers of the Truck-Stop, and for Mark's support for the society, he has been presented with a certificate of appreciation from the society. Hopefully we can look forward to presenting more of these certificates in the near future

The Fifth Wheel Truck Stop is located at the Waverly Road Exit 431, Bowmanville on Highway 401 in Ontario.

***If you know of a perfect place where one of our collection boxes might prove popular please contact the society—see back page for contact details***

*A chance to influence the future of the society, meet other members and give a genetics research blood sample all at the same time.*

## ANNUAL GENERAL MEETING: SAT. NOV. 24th 2007 11a.m. AT THE BRITANNIA HOTEL, NEW STREET, BIRMINGHAM, U.K.

The first A.G.M. of the Pernicious Anaemia Society is to be held on Saturday the 24th November at The Britannia Hotel, New Street, Birmingham at 11 a.m..

Not only will the event provide members with the opportunity to discuss the future of the society but it will also give attendees the chance to meet fellow members and sufferers.

The meeting will be scheduled for the morning when most of us sufferers are at their best, and it is anticipated that the meeting itself will not last longer than an hour or an hour and a half.

The meeting is important for two reasons. Firstly, it satisfies the requirements of the Charity Commission that all members of the society are invited to attend.

Secondly it marks yet another milestone in the society's development—it's a year since being recognised as a charity.

A third reason is that two doctors connected with the research into the Genetics of P.A. will be present to take blood samples for analysis. Please make an effort to attend this important event.

## NEW INTRODUCTORY INFORMATION LEAFLET AVAILABLE

One of the most frequent requests received by the society is made by fellow sufferers of the condition asking for information about the condition.

For over a year the excellent article written by two of our members has provided a detailed lay-person's guide has served the purpose of providing just the information that people with the

condition need to know.

Now, with funds supplied by a small lottery grant, a new, more concise leaflet has been produced that can be deposited in any place that sufferers of Pernicious Anaemia might visit.

Hospital Haematology or Pathology Departments, Pharmacies and G.P. Surgeries are all potential

sites where people with an interest in P.A. could find a quick and concise explanation of the condition and details of how to contact the society.

To order your leaflets contact us—details on the back page.



**Please help us to help fellow sufferers by placing our leaflets at strategic locations.**



P.O. BOX 245  
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Phone: 01656 720187

E-mail:

[chair@pernicious-anaemia-society.org](mailto:chair@pernicious-anaemia-society.org)

**Bankers:**

**Natwest, 28 Adare Street, BRIDGEND  
CF31 1EN**

The Pernicious Anaemia Society exists to provide support and information for people with Pernicious Anaemia, their family and friends. It is registered with the U.K.'s Charity Commission, registration number 1115195.

Membership of the charity is free and roughly one third of members are from outside of the U.K. and the vast majority of these members are from the English speaking world.

We want to involve members of the society as much as possible and if you would like to contribute to this newsletter please contact us—any offer of help in any way is always warmly received.



## **New Information Leaflets Available from The Pernicious Anaemia Society Information Library.**

A new series of Information Leaflets that provide information about various aspects of Pernicious Anaemia are now being developed.

Two such leaflets are available now. One provides information about **Self Injecting**. The other provides details of **Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia**.

These leaflets are available in P.D.F. format or as a hard copy.

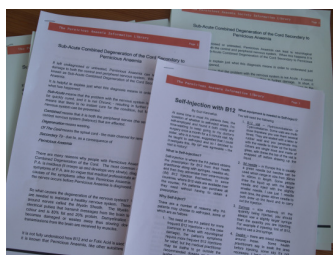
Over the next few months more leaflets that target particular aspects of living with Pernicious anaemia will be published including the following:

- 1. How to get more frequent injections of B12.**
- 2. Pernicious Anaemia and other**

**Auto-immune diseases.**

### **3. Coping Strategies for dealing with Pernicious Anaemia.**

If you can identify an issue relating to Pernicious Anaemia that you think would be helpful to fellow sufferers please contact the society with your suggestion. If you can



**The Pernicious Anaemia Information Library will expand in the next few weeks.**

write a guide that deals with the issue then obviously that would be even better and you will be doing your own bit to help patients of the condition to better manage their everyday lives.

If you require a copy of the leaflet on Self-Injection or on Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia please contact the society as outlined above.

If you require a hard copy of any article please include a first class stamp to help us offset the cost of printing and postage.

Finally, feel free to print out multiple copies of this newsletter and distribute them wherever you feel people will benefit from it.