

**Awareness Week
Special Edition**

**AWARENESS
WEEK**

26-30

OCTOBER

2009

Get ready to
help!

Lobby your MP

Attend the
Parliamentary
Reception

Help bring
about change

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Cobalamin News

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P.A.S. HOSTS PARLIAMENTARY RECEPTION

The society has been successful in its appeal to host a Reception in the Palace of Westminster.

The Reception will take place in the Jubilee Room within the House of Commons at 9.a.m. on Wednesday 28th October.

Wednesday 28th October has been designated **Pernicious Anaemia Awareness Day** and is in the middle of the Pernicious Anaemia Awareness Week that runs from Monday 26th October until Friday 30th October.

The Reception will provide the opportunity for interested members of the society to accompany their Member of Parliament to the Jubilee Room on the morning of the 28th October. The Member of Parliament can then be introduced to the Trustees of the Society and will be able to understand the problems our members face in relation to the Symptoms, Diagnosis and Treatment of Pernicious Anaemia.

The Reception will also provide the opportunity for members of the society to encourage their M.P. to sign the **Early Day Motion** that will



The Reception will be held within Parliament

have been tabled. The E.D.M. calls for a thorough and urgent review of the symptoms, diagnosis and treatment of Pernicious Anaemia and is based on the findings of the **Review** that was published in the spring of this year.

This event on the Wednesday of Awareness Week will be followed by a private screening of a feature film that was made by one of our members who, because of the inadequate

treatment regime, struggled to complete the film during the afternoons of the shooting.

After watching a short excerpt of the film at 1p.m. in a Committee Room, members of the society will have the opportunity to lobby their M.P. to support our cause.

We urge our members to become involved in the Awareness Week.

If you are interested in attending any of these events please contact us for further information. See inside for instructions on what we want you to do.

Writing to your M.P. would help, but if you are able to make it to London please make every effort to do so.

We might even be able to put you in touch with other members of the society who might live near you and so car-sharing might be an option.

This is the culmination of a lot of 'behind the scene' lobbying of politicians and is our best chance yet to get the current antiquated treatment reviewed.

Information Packs Now Available

The society has been hard at work putting together a special **Lobby Information Pack** that is available to members.

The idea is that these packs will be made available to all those who would like to take part in the Awareness Week in order to maximize our effectiveness during the political lobby.

The packs contain the following lobbying aids:

A **Briefing Sheet** that you can send to your M.P. The sheet outlines the basic problems that we, as sufferers, face relating to the Symptoms, Diagnosis and Treatment of Pernicious Anaemia. Giving this to your M.P. will make him or her aware of our problems and encourage him or her to sign the Early Day Motion.

An **example of a letter** sent to an M.P. that you can use as a

model for your letter to your M.P.

A **statement** by the Chair of the society that outlines the benefits of reviewing the current diagnosis and treatment of Pernicious Anaemia.

We will also include a stamped addressed envelope to your Member of Parliament—but you need to contact us first—see back page for contact details.



An excellent chance to meet your elected representative.

We'll supply all you need to take part in getting the problems with P.A. onto the political agenda.

Early Day Motions are used to highlight problems with issues but are rarely debated in full.



HOW YOU CAN HELP:

A number of Westminster M.P.s are now convinced that there is an urgent need for a review of the symptoms, diagnosis and treatment of Pernicious Anaemia. One M.P. has tabled an Early Day Motion that states this.

We want as many M.P.s to sign that Early Day Motion to show that they too, believe that there is the need for a review of the symptoms, diagnosis and treatment of Pernicious Anaemia.

So, what we want you and

your families and friends to do is to contact your M.P. and tell him or her about the problems we, as sufferers, face. We, as a society, can provide you with the name and contact details of your M.P.—just call us.

We can also send you a Briefing Sheet for you to pass on to your M.P. that states the major concerns that we have.

You then tell your M.P. about the Early Day Motion that will be tabled on Wednesday 28th October and ask him or her

to consider signing it.

It's important to note that the more people ask their M.P. to support the Early Day Motion the more chance there is that he or she will sign it.

There is almost no chance whatsoever that the Early Day Motion will become the centre of a full House of Commons Debate; but what it will do is demonstrate for the first time that there is political support for a review of the diagnosis and treatment of Pernicious Anaemia.

WHAT YOU NEED TO DO NEXT:

Step One: If you don't already know the name and contact details of your M.P. then please contact us by telephone on 01656 724163.

Step Two: We will send you an Information Pack that will include a stamped addressed envelope with the address of your M.P.: A Briefing sheet for you to send to your M.P.: an example of a covering letter and other contact details such as email address, telephone number, fax no. etc.).

Step Three: You (and hopefully your friends and family) will write a letter to your M.P. asking him or her to support and sign the Early Day Motion and, if you are planning to take part in the Parliamentary Lobby and attend the Reception you will also ask him or her to meet you in the House of Commons on Wednesday 28th October between 9 a.m. and 11 a.m. and /or at the screening at 1 p.m. or after the

screening in an allocated Committee Room.

Step Four: You (and your family members and friends) will send the letter to your M.P. using the stamped addressed envelope that we provided you with in the information pack. You will also enclose the Briefing Sheet and your contact details. Don't forget—the more letters he or she receives the more successful we will be.

What is an Early Day Motion?

An Early Day Motion is a Motion, tabled by a Member of Parliament to be debated 'at an early day' - that is sometime in the near future.

Very few Early Day Motions are ever debated on the floor of the

House of Commons but they remain open for other Members of the House to sign for the duration of the Parliamentary Session.

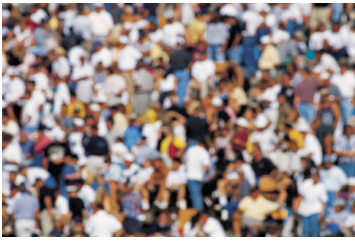
Getting your M.P. to sign the Early Day Motion demonstrates that he or she supports the motion, even if there is hardly any chance of

the motion being debated in the chamber.

There are 646 members of parliament and only four Early Day Motions have attracted over 400 signatures.

Hopefully, with your support, we can add to the number of Early Day Motions that received over 400 signatures.

GET INVOLVED—and get others involved:



The aim of the political campaign is to get politicians and medical professionals to look again at how Pernicious Anaemia is diagnosed and treated.

The diagnosis and treatment of Pernicious Anaemia have not been

Now is the time to help change the way we are diagnosed and treated!

carried out in order that a swifter, more accurate diagnosis is made and the treatment be centred on the needs of the individual and not on an outdated medical textbook.

If we are to be successful then we will need as much support as pos-

significantly changed for over fifty years. And with new technologies available it is time for a systematic review of the condition to be carried

sible. And that means enlisting not only the support of all our members, but also the friends and family of members need to get involved as well. After all, Pernicious Anaemia does not only affect the patient with Pernicious Anaemia but also it impacts on family and social life.

Please help us to change things and do encourage your family and friends to get involved in the political lobby. We welcome the involvement of anyone with an interest in Pernicious Anaemia—not only those who suffer from the condition.

“Hopefully this will be the catalyst for change throughout the world”

What if I live outside the U.K?



Between 25% and 30% of our members who joined online live outside the United Kingdom. Of these the majority are living in the English-speaking world—although apart from Antarctica we have members on every continent. The society's Trustees are proud of this international perspective and this is mirrored in the international composition of the Management Council that meets online

every two weeks.

However, as the society is based in the U.K., and all of its resources are in the U.K. it is not possible for us to launch political campaigns in other countries.

This is a new venture for the society and we are 'in uncharted waters'. What is hoped is that this exercise will be a catalyst for change in the treatment and diag-

nosis of Pernicious Anaemia.

And of course, if any of you who live outside the U.K. want to do your bit to get Pernicious Anaemia onto the political agenda please get in touch. We can help you with promotional materials and advice.

Remember that this is the *Year of B12 Deficiency* and we all face the same problems in the diagnosis and treatment of P.A.

Who will be involved during Awareness Week?

Easy—You! You will be our most important asset during the Awareness Week. Your letters and involvement in the lobby at Westminster will count more than the involvement of any celebrities (although any help from that quarter would be gratefully received).

But as well as our membership we also have the support of a number of M.P.s, who will be available to

meet our members on Wednesday the 28th October. The Members of Parliament will play the crucial role of placing the problems faced by patients onto the political agenda.

“Doctors talk and listen to doctors” is how one medical negligence solicitor described the problem we face when trying to highlight this issue. But it is also

the case that they **have to** listen to their political masters.

Also in attendance on the 28th October lobby will be Sally Pacholok—the author of 'Could it be B12' and other medical professionals who are already sympathetic to our cause.



You are more important than any 'celeb'.



The Pernicious Anaemia Society

The Old Fire Station

Pandy Park

Aberkenfig

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WANTED—YOUR STORY!

During the few weeks before the Awareness Week we will be highlighting the problems associated with Pernicious Anaemia and vitamin B₁₂ Deficiency. We desperately need members to talk to the various media that we will be using to publicise our cause.

We are especially interested if you have suffered from being wrongly diagnosed, or non-diagnosed for any amount of time.

Perhaps you have suffered permanent nerve damage due to your lack of diagnosis or treatment—if so we would like to hear from you.

We are also interested in any young members who feel that their schoolwork and socialising is being badly affected by the treatment. Maybe you have sought an alternative treatment

regime in the private sector such as B₁₂ infusions and are now self-injecting regularly. If this is you, or if you know anyone who has chosen this route then, once again, we would really like to hear from you.

Perhaps you are struggling on the three monthly treatment regime and your work and family life is being adversely affected.

And there is one other category of member that we are desperate to talk to—those elderly patients who are suddenly told that, because they have reached a certain age, they no longer need any injections.

Remember, you must be prepared to talk to journalists—we will prepare you for this and can offer training on being interviewed. Please consider this request carefully—you may even be able to remain anonymous. We all have a story to tell—now's the time to tell it.

New Members & Website Updates

Our membership continues to grow. We now have over four thousand members from all over the world although the majority of our membership remains British. But it doesn't matter where you are from, the problems faced by our members in relation to the condition are the same wherever you live.

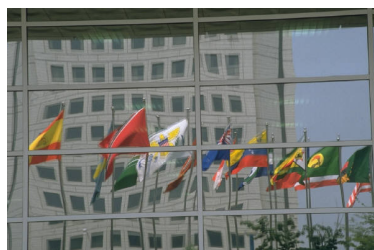
The small, one-off lifetime membership fee that was introduced at the beginning of the summer means that, for the first time, we now have a steady stream of sustainable funding.

However, that doesn't mean that we are financially well off. We are still struggling to meet the increasing demands for our information leaflets, and postage costs. And of course, the website doesn't maintain itself.

Although the demands for information, help and support from our members and their families and friends continues to

grow, we are able to keep up with the demands entirely by using volunteers. We still have no paid employees and it is thanks to the help and dedication of our volunteers that the society keeps providing this unique source of information.

Please consider giving a donation to help us continue to help people with



We are a truly international charity with over four thousand members that continues to grow daily.

P.A. or their families and friends. It's very easy to do. You can send a cheque made payable to *The Pernicious Anaemia Society*, or use the credit card payment facilities to make a one-off payment on the homepage of the website. Or, alternatively you might like to join the growing number of members who make a small, regular (monthly) donation using a bank standing order. Please contact us for a Gift Aid form so that your donation will mean even more to us.

Should you require any information about leaving the society a legacy do get in touch so that we can advise.

If you haven't visited the website for a while you may like to pay a visit where new features such as *News Events* and the *Chairman's Blog* can help keep you informed of all the latest developments taking place.