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we care*

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# Sussexia

## AGM 2014

### Saturday 22<sup>nd</sup> March 2014

### Doors open at 1.30pm

### St Paul's Church Hall

Churchside, Chichester, West Sussex PO19 6FT.

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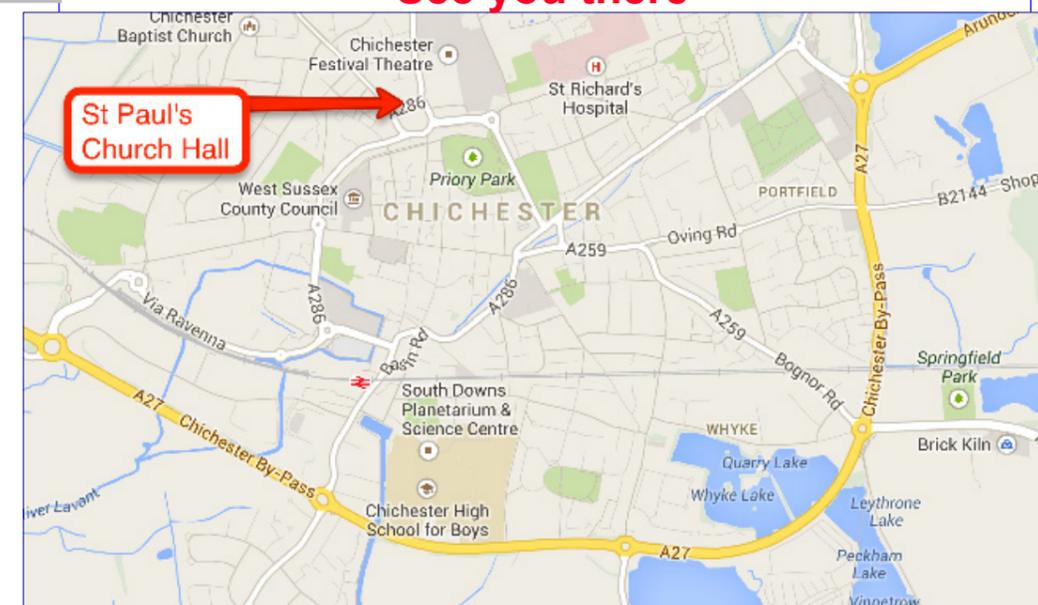
*Please come and  
make this a really  
good AGM.  
March 22<sup>nd</sup>, doors  
open 1.30pm*

Special interest to possibly the younger members is the speaker this year. We have Mr Jeremy Clark, a Colorectal Consultant Surgeon from Brighton, giving a talk on Ileo anal pouches. This will be really good especially for those thinking about that surgery.

Great interest to our younger members is the possibility to meet your new Young IA Representative for Sussex IA. Please come and welcome him to the role providing he is able to attend.

There will be the usual display by the suppliers as well as refreshments and a prize raffle. Come to Chichester and make a day of it.

**See you there**



## Romania Ostomy Patients Support Foundation

It was nineteen years ago following discussions with IA's president that member organisations voted to support ostomy patients in Romania and raise a sum of £40,000 in celebration of 1996 World Ostomy Day and IA's own fortieth birthday. Of the original team two IA members remain in what has been an interesting and at times challenging project, now of course a separate charity, the Romanian Ostomy Patients Support Foundation but with the same aims as that initiated by IA.

*The lives of Romanian stoma patients have been helped tremendously by the work of ROPSF*

When the original Romanian invitees were welcomed and the team's first visits were made to Romania, language and first-hand knowledge of the country was scant, what was known was based in the main on the parlour state of the country following the overthrow of the tyrannical Ceausescu regime and its subsequent aftermath. Meetings with surgeons, nurses and carers quickly brought to light the enormous gulf between the support for patients as we in the west know and expect and the serious shortcomings of ostomy patients in Romania. The surgical skills were in place as was nursing care but stoma knowledge and the needs of the patients were dire. Appliances were virtually non-existent leading to reclusive living with little chance of an acceptable lifestyle for stoma patients - all too often ostracised. Patient Support Groups such as Sussex IA just did not exist - a worthy reason for IA to offer support drawing on 40 years' experience.



*Hospital in Constanta on the Black Sea Coast.*

Over the years much in Romania has changed; appliances are prescribed, albeit inferior to those that we would expect, patients are presenting much earlier and surgery offers a better chance of survival. Training of nurses in stoma care through IA/ROPSF has helped to ensure that care has been greatly enhanced. On this topic alone ROPSF managed to raise sufficient funds in 2012 to bring over eleven senior nurses from eleven different hospitals and train them as trainers in stoma care. This has been a most successful exercise and on a return visit to Romania last year there was strong evidence that this was having an affect with many more junior nurses having a better understanding of the need for stoma care.

The ROPSF team know that their hard work is paying dividends and as a poignant reminder when we visited the principal hospital in Constanta the Head Nurse to our delight was a young lady who IA trained in the late nineties: it was an even greater surprise to find that the Medical Director was a surgeon who had been invited by ROPSF to the UK to witness stoma surgery back in early 2000. Both are most supportive of the needs of ostomy patients and of the training that ROPSF has provided.

Of late ROPSF has added to the team with new members from IA, the Colostomy Association and a representative from the paediatric stoma care group and to complement this group we now have two well qualified Romanians who work in the UK as part of the team. As an ongoing strategy ROPSF is always looking to add further skills to the team as there is still much to achieve.

**If anyone would like to help then please contact Bob Bailey for more information via Dave Drakeley**

*Picture: left to right Irene Anderson, Reader in Nursing University of Hertford, Bob Bailey, Dr Gasa(Chief Medical Officer), Cristina Asofie(Chief Nurse), Iuliana Jecu(Stoma Nurse).*



## Dave's Ramblings

Has anyone any ideas at all about any sort of meeting they would like us to organise. It can be formal or informal or social. whatever you want we will look at and try to accommodate the suggestion. We want this group to have more contact with each other and us on the committee.

### Standing orders

There are still some of you that haven't changed your standing orders to the new subscription rates so please do that soon.

If any of you that don't already do it and would like your subscriptions paid automatically the please ask for a form from Dave Drakeley which you then complete and take to your bank. Unfortunately we don't do Direct Debit so Standing Orders is all we have.

### AGM transport problems?

**Would you like to come to the AGM this year but can't get there?**

**Would you come if you could be given a lift?**

Please contact a member of the committee whose contact details are on page 4 of this newsletter and we might be able to sort out a lift for you. I cannot promise but we will try but we do need to know in advance because if you ask on the morning it will not give us enough time to arrange things successfully.

### Prize Draw ticket

As you will have seen, there are a couple of books of draw tickets accompanying this newsletter and Journal. Please return the sold ticket stubs and money to Dave Drakeley by April 19<sup>th</sup> so that they can be sorted and sent off in time for the draw. If you no longer wish to be sent tickets and return them please enclose your name and address so they won't be sent next year.

### Visiting skills course

Hi, when you had your stoma forming surgery, were you offered a visit from someone who'd had similar surgery to you and if so, did you find it helpful or not? The IA has a visiting course which is endorsed by the UK stoma nursing organisations and offers structured training to any of you who would be interested. For many people, having a visitor to talk to has proven to be a very positive experience and the impact cannot be underestimated. BUT, it is also important that the visitor has the skills necessary to ensure that this is a positive experience and not a chance to focus on the negative aspects of their own experience / surgical journey. The IA offers a one day taster day so that interested parties can see what's involved and decide whether they would be interested in moving forward as a IA visitor. Currently, there are no taster days organised but if we have enough interested members then Ann Demick, national secretary, would be willing to come and speak at any meeting we could organise. With the enhanced recovery programmes, patients are spending less time in hospital and this is where I believe, a carefully trained and selected visitor could make a positive difference to the recovery of a patient. We do have some leaflets with more information if interested and you can obtain these from me or Dave, I will also have some with me at the AGM in Chichester.

*Written by Jane Myer, Stoma Nurse.*

*Standing orders are the only form of automatic payments we have*

*Visitors are a very important part of what IA does and we are always in need of a wide range of visitors with training*