Welcome …

to the latest edition of the Breastfriends newsletter. We hope you will find lots to interest you. We have a variety of speakers coming up and we look forward to seeing you at meetings!

Emma Burns Chairperson

MARKS & SPENCER SPRING LINGERIE EVENING
18 APRIL 2011
7.00 PM

We are having our annual Spring Lingerie evening at Marks and Spencer (Culverhouse Cross) again this year. This is instead of our April evening meeting. All proceeds from the evening raffle will go to Breakthrough Breast Cancer.

In the meantime, M&S are having a "Get fitted, get rewarded" event retraining their bra fitters to give an even better service and they would like some "real" customers to help!

As a thank you for taking part they will give everyone a £10 voucher to spend on lingerie. If you are interested you can contact Culverhouse Cross store for details. The next date will be 28 July 2011.

MARKS & SPENCER

We want this to be your newsletter so if you have any ideas, comments, questions, or articles/information, please don’t hesitate to contact us (see back page)!

NEW BREAST UNIT OPENS AT LLANDOUGH HOSPITAL

On 25 October 2010, the first patients were admitted to a new £1.5m one-stop breast clinic at Llandough Hospital, where women – and men – who discover they have a lump in their breast will be able to have a mammogram and ultrasound on the same day as their initial appointment.

Patients and professionals alike have welcomed this first class facility, the only centre of its kind in South East Wales. The centre modernises the service considerably and will make a huge difference to the care provided to breast cancer sufferers.

Previously patients have had to attend appointments at Llandough Hospital and the University Hospital of Wales, Heath, Cardiff, usually over a number of days or weeks which increased anxiety at what was already a very stressful time.

Sumit Goyal, a consultant breast surgeon at the centre, is reported as saying: “This one-stop shop means that patients can have their mammogram, their ultrasound or clinical examination on the same day.

“This is a very stressful time for patients and we need to do all we can to reduce that stress in the environment of the centre.

“We have counselling rooms with their own exit door because someone who’s crying doesn’t want to walk back through a crowded waiting room.”

“It also offers a very relaxed atmosphere and we hope it will help to calm understandably anxious people”.

Breastfriends is adding to the ambience of the centre by providing subscriptions to the following magazines: Woman & Home, Gardener’s World, BBC Wildlife, Red and Hello.

The new centre will also allow experts to carry out research into new treatments, and discussions are under way to provide some chemotherapy at Llandough Hospital, instead of at Velindre Cancer Centre.

INSIDE:

pages 2—3: Wales Cancer Alliance; Breast Cancer Care Fashion Show; Macmillan Survivorship Project
page 4: Breakthrough Breast Cancer Updates
page 5: Book Review
page 6: Breast Cancer Care Services and News
page 7: Breastfriends Personality; Breast Cancer Care Younger Women’s Forum
page 8: Next meeting dates
WALES CANCER ALLIANCE

As we approach the election in May, the Wales Cancer Alliance (an Alliance of cancer charities in Wales of which Breast Cancer Care is a member), has been campaigning for all Parties to include an all Wales patient-centred cancer plan for Wales in their manifestos.

This includes the establishment of a ‘leader for cancer’ to be appointed at a senior position within the government to drive the plan and implementation in order to ensure the best possible care and treatment for those diagnosed with cancer rather than the patchy and fragmented care which can be available.

The plan should ensure a holistic approach for each patient taking into consideration all their needs throughout the treatment pathway including post treatment.

Three of the parties have included this commitment in their manifestos and an event was scheduled for 22 March at the Senedd where each Party will be asked to respond to questions and outline how a patient-centred plan would be delivered.

An update from this event will be included in the next newsletter.

BREAST CANCER CARE FASHION SHOW

In February 2010, Breast Cancer Care held its first fashion show in Cardiff. It was a fabulous glittering event made extra special by the fact that all the models had had breast cancer. Breastfriends committee member Jane Millar tells us what it was like to be a model and why she firmly believes that Breast Cancer Care should built on the success of ‘The Show’ by holding a high profile corporate event each year:

The Welsh Fashion Show was one of the most amazing experiences of my life! I feel so lucky to have had the opportunity to take part and meet some marvellous men and women – and not just the models but those contributing to making the evening a success for Wales and Breast Cancer Care.

What hit the models as they walked out on the catwalk was the most amazing sense of warmth, comfort and generosity from an audience of family, friends and key business people from South Wales. I was in a group who performed a number of dance routines, which had me totally out of my comfort zone, but it didn’t matter! The applause did not stop from the moment we started to when we received the most wonderful bouquets.

The Show brought Breast Cancer Care to the front of the minds of those attending and those we worked with along the way. The South Wales Echo coverage was huge, leading in to the event and afterwards with a number of the models becoming stars! It has not just been about the money raised but the profile and the services that can be provided; which is why I, along with a great group of others, are determined that such an event happens in the South Wales region every year. Sadly there will never be a shortage of models who have experienced a diagnosis of breast cancer, but I have learnt that this brings together people who want to work to make it better for others.

This year, Breast Cancer Care are having a ‘Ritz style’ Strawberry Tea in Duffryn Gardens on June 9th to engage with the business community of South Wales. We want to work with the business community not just to raise money but also to explore the services that we can provide through them. Our focus is to have a Welsh Fashion Show again in 2012 and the business community support is essential for this to be a success.

If anyone wants to contribute to taking these events forward, please email me: jmi@ihcso.org

Jane Millar
**MACMILLAN SURVIVORSHIP PROJECT**

**Macmillan campaigns for** a better deal for people affected by cancer and wants everyone with cancer to receive the right level of treatment and support, regardless of who they are and where they live.

**Living with or beyond cancer**
There are two million people living with or beyond cancer in the UK. This figure is set to rise to four million by 2030. It’s a cause for celebration that more people than ever are surviving after a diagnosis but Macmillan knows that the impact of cancer does not suddenly stop when treatment is over.

**Macmillan and survivorship**
Macmillan believes that people living with or beyond cancer, and their carers, should have easy access to high quality care, treatment and support to meet their medical, practical, emotional and financial needs for years after treatment. They should be respected and included as equal members of society and be able to take as active a role as they wish in their care and treatment.

**How does Macmillan believe people living with or beyond cancer should be supported?**

- Macmillan believes that all people living with or beyond cancer should have access to the following:
- A post-treatment assessment care plan and appropriate medical, practical and emotional services for everyone who finishes treatment or is diagnosed with active, progressive or recurrent cancer. This should also include information regarding employment after cancer
- High-quality information and the tools to help people support themselves throughout their cancer journey
- Advice and support to help people get back to work
- Support for people experiencing physical or emotional consequences relating to their cancer or its treatment
- Timely access to psychological therapies to address any mental health issues

**Access to specialist medical care for complications that occur after cancer**

- Support for carers, including assessment of their needs
- Involving people living with or beyond cancer in the development of services
- Health care, social care and voluntary organisations working more closely together to help support people living with or beyond cancer.

**What is Macmillan doing already?**

- Macmillan has partnered with the Department of Health, supported by NHS Improvement, to create the National Cancer Survivorship initiative; a key initiative of the Cancer Reform Strategy (2007), working to improve services for cancer survivors in England.
- Macmillan is providing information and support through its information and support services across the UK, its publications, websites, cancer support specialists and through its network of Macmillan professionals.
- Macmillan is providing financial help through one-off grants and benefits advice.
- Macmillan is giving people the skills to manage their own condition through its New Perspectives programme and supporting over 800 self-help and support groups across the UK.
- Macmillan is working with local partners and governments to help develop understanding of the needs of cancer survivors.

**Skills for living well project**

The project is being run by experts at Velindre Cancer Centre, funded by Macmillan Cancer support and is available across the South East Wales Cancer Network. It is part of a UK wide venture to improve support for people with cancer.

Group sessions are available at many venues within the South East Wales area, though none will be held in hospitals. Venues include hotels, social clubs and golf clubs.

There is no charge to attend the session.

The participants will be invited to attend just one of the sessions which will run for about 2 hours. Session times will depend upon the venue, though most are held during the day.

The sessions will be run by specially trained volunteers all of whom have personal experience of cancer either as a patient or a carer. The training has been provided by a Consultant Allied Health Professional who specialises in cancer rehabilitation and an experienced Therapies Manager who works with cancer patients.

As it is a project, it is important that the sessions and their impact upon the attendees are evaluated and so it will be necessary for you to answer some questions on these things as your views are really, really important and can help shape future work.

Refreshments will be provided. At the end of the session you will be provided with a handbook which contains all the advice you will have heard about during the session, and it is hoped this will of use to you in the future. (from Velindre Cancer Centre, www.wales.nhs.uk)
In 2008 around 22,900 women aged between 50 and 69 were diagnosed with breast cancer – almost half (48 per cent) of the total number of cases. Around 15,700 cases (33 per cent) were diagnosed in women over 70 and 9,100 cases (19 per cent) in women aged 25-49.

Lifestyle factors and having a family history of the disease increase a woman’s risk of breast cancer.

Today, women tend to have fewer children later in life and this too increases risk.

Dr Rachel Greig, Senior Policy Officer at Breakthrough Breast Cancer, said:

“These figures are a wake up call and should not be ignored. More women are developing breast cancer and, although survival is improving thanks to breakthroughs in breast awareness, screening and treatment, we clearly have much further to go. A two pronged attack is needed - commitment to research into the causes of breast cancer, supported by women arming themselves with knowledge of the risks that may contribute to the disease.

“Some risk factors, such as getting older, cannot be changed but the good news is that others can. By drinking less, maintaining a healthy weight and getting physically active, women can reduce their risk of developing breast cancer.”

A better understanding of the causes of breast cancer.

Scientific evidence indicates that the causation of breast cancer involves a complex mixture of factors – some to do with behaviour, such as lack of exercise, some to do with environment and some genetic (inherited). These factors act at many different stages of life, probably starting before birth, and continuing to the menopause and beyond.

To find out what these factors are, and how they combine with each other to cause breast cancer, a study is needed in which information about the factors, and how they change through life, is related to the risks of subsequent breast cancer.

A large study has therefore been set up as a partnership between The Institute of Cancer Research and Breakthrough Breast Cancer to investigate the causes of breast cancer.

For more information visit www.breakthroughgenerations.co.uk

Breakthrough’s Service Pledge for Breast Cancer
Enabling breast cancer patients and healthcare professionals to work together towards better local breast cancer services.

Breakthrough’s Family History campaign
Ensuring that women with a family history of breast cancer have access to the best possible services available.

Screening Saves Lives
Improving the early detection of breast cancer by pressing for continued improvements to the NHS Breast Screening Programme.

Every Chance
Ensuring every patient has every chance to beat breast cancer.

Left in the Dark
Ensuring women with breast problems referred by their GP do not wait longer than two weeks to see a specialist.

Tell us what’s important
for people affected by breast cancer today.

CURRENT CAMPAIGNS

If breast cancer is to be prevented, its causes must be found. The Breakthrough Generations Study is the most comprehensive study ever undertaken into the causes of breast cancer.

Why is the study needed?

Nearly 46,000 women are diagnosed with breast cancer each year in the UK and the numbers are increasing. Many of these could, in principle, be prevented, but to do so we need to gain a
BOOK REVIEW

Cancer is a word, not a sentence. Dr. Robert Buckman. Collins, 2007. 248 pages

Now, here’s a book I wish I had read when I was first diagnosed, almost three years ago. It guides the reader/patient through the first day of diagnosis, possible routes of treatment, to (hopefully) recovery and moving on with your life. The book focuses on regaining your control, something that is lost instantly when you are told you have cancer, and you then put your life into the professionals’ hands. The author, Robert Buckman, is a British-trained oncologist working in Canada, but the statistics and resources in this book are UK-based. His main premise is that you must not panic (indeed, there is no need to panic), and that you can fight panic most effectively with clear information.

The book is set out in six sections, in addition to the appendices (tables, including types of blood tests, common drugs, and the “current generation of biologics”), directory of resources (all UK-based), and a very small list of other useful books. It seems to include all the things I wish I had known to ask from the beginning. Some of the information is difficult to follow if you are new to this, and some chapters are more comprehensive than others.

Part One is a step-by-step guide: how diagnosis is made, all kinds of follow-up scans, what kind of treatment you might follow (including surgery), how to make “your” decision about treatment, and recurrence. I assume this would be one section updated for any later editions.

Part Two deals with the logistics of how cancer is treated: what it’s really like, from surgery to radiotherapy, chemotherapy to biological agents (i.e. Herceptin) and clinical trials, side-effects of drugs, long-term effects of treatment. It explains who the members of your medical team are (or should be). There is a lot of information in this chapter, and it might be too overwhelming to read all at once, but should be very useful for reference. Part Three discusses complementary medicine and remedies.

and, here, Buckman’s writing is brief and rather obtuse. The gist of his ideas is stated at the end of the chapter: patients should try complementary remedies “as long as they have realistic expectations of it,” and that it is absolutely not proven that complementary remedies, as opposed to conventional medicine, can reverse, halt, or cure cancer of any kind.

Part Four is about living your life during and after treatment, and is part common sense and part life-coach. Buckman includes, among others, topics such as sex, emotions following diagnosis, surviving vs. thriving, planning for the worst and hoping for the best, spirituality, how to find and get support, and how to talk to children about cancer. My favorite topic in this section is “don’t rush back to work!” Although I find this chapter very useful, there is one glaring omission: there is no mention of exercise at all. Perhaps Buckman thinks this is outside the scope of initial recovery after treatment, but I found that exercise was the first thing I wanted to get back to after a year of stress, worry, drugs, and surgery! Finally, Buckman discusses “how do I ask for what I want?” This should be addressed in Part One, as this is something we need to be able to do from Day One.

Part Five is about cancer and the mind, thinking positive, and the myth about stress. What kept coming to mind as I read this section was the question “do we have to be brave?” Do we have to be positive all the time, or can’t we just do as we are told, show up for our appointments, take all the drugs, and eat well? This works well for some, whereas, for others, the mindset is everything. I think each reader will get something different from this chapter.

Part Six, about how to gain more control over your life, could easily have been incorporated into Part One: sections on friends, support groups, internet information (being careful with this one, as there is so much bunk out there!) might be useful to read early on, not just after treatment and when you are on the road to recovery.

The Appendices include the aforementioned tables (the ones on common drugs and current biologics are likely to change as research progresses) and a directory of UK-based resources, including websites. The Further Reading list is small, and includes Jane Plant’s Prostate Cancer and Susan Love’s Dr. Susan Love’s Breast Book. The index in this book is extensive, but I noticed some odd entries as well as some omissions: diet gets one page even though it is discussed in other pages in the book; fertility and exercise have no entries - even the pages cited for “children” do not discuss fertility; and, although you can look up “lumpectomy,” you will not find WLE or wide local excision.

Buckman is unequivocal about one thing: stress does not cause cancer, and has very little effect on how well your treatment works and how quickly you recover. This is good news for those who struggle to be “positive.”

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For breast cancer patients, this book a good place to start if you are at a stage where you can cope in the amount of general cancer information it offers, but there are more comprehensive books on breast cancer out there. Despite this, it is a useful reference guide to information about all kinds of cancer treatments. Read Part One first then Part Four (then the rest of the book) and don’t forget to live your life! Liz Reyes

Cancer is a word, not a sentence. A six-step, practical guide.
Dr. Robert Buckman
Foreword by Dr. Miriam Stoppard

“...around half of those people diagnosed with cancer in the UK will be successfully treated and most of those will not be troubled by it for the rest of their lives.”

Have you read a book that has inspired you? Would you like to review it for our next newsletter?
Contact us: info @breastfriendscandv.org.uk
Deadline for submissions for the next newsletter is Friday, 27 May, 2011.
Breast Cancer Care has produced a new resource pack for patients living with and beyond breast cancer which discusses a range of topics that may be relevant to you after treatment for primary breast cancer.

From signs and symptoms of recurrence to dealing with fatigue and financial issues, this pack offers practical solutions and sources of further support, to help you move forward with more confidence.

Whether you have just reached the end of your treatment or your diagnosis of breast cancer was several years ago, this resource is for you.

It also contains our DVD 'Getting fitter, feeling stronger: exercises to help recovery after surgery for breast cancer' and the personal experiences of four women about how they've moved forward since their treatment for breast cancer.

To order a copy phone 0808 800 6000 or visit www.breastcancercare.org.uk

SECONDARY BREAST CANCER

Breast Cancer Care set up the Secondary Breast Cancer Taskforce in May 2006 to improve the treatment, support and care of people living with metastatic breast cancer by influencing policy, raising awareness of good practice and promoting optimum services.

It is a national coalition of healthcare professionals, government representatives and, most importantly, people living with metastatic breast cancer.

Breast Cancer Care is committed to working to improve the care and support available to metastatic breast cancer patients, and hopes that by facilitating a discussion, it can begin to take steps to benefit this patient group.

Breast Cancer Care Cymru was scheduled to hold an event on 28 March to bring together senior figures with an interest in patient care to discuss the recommendations of the Secondary Breast Cancer Taskforce.

Senior government officials, leading clinicians and members of the Wales Cancer Intelligence Surveillance Unit were invited to attend.

An update on this event will be included in the next newsletter.

CARDIFF HEADSTRONG SERVICE

For many people, losing their hair as a result of treatment for cancer can be the most distressing side effect. Headstrong is a free service which provides practical support for anyone experiencing hair loss due to cancer treatment.

HeadStrong volunteers show clients how to cope better with hair loss by demonstrating a range of headwear, including scarves, hats and hairpieces. Clients are also given information about hair loss, scalp and hair care.

Appointments are available on Wednesday afternoons at Breast Cancer Care and last up to one hour. To make an appointment, contact the Cardiff office on 0 2 9 2 0 234070.
Every issue we would like to feature a Breastfriends Personality. Thanks to Emma for volunteering for this issue!

Emma Burns, Chairperson of Breastfriends

Like everyone else involved in running Breastfriends, I have a personal experience of breast cancer. In fact, it is 10 years ago this year that I was diagnosed. Ten years ago I was very worried that I wouldn’t be here to write that sentence and yet, here I am...that makes me feel very positive! I was only 30 when I was diagnosed and didn’t fall into any of the typical risk groups for breast cancer. I was young, had no family history, had my baby at a young age and breast fed him for ages. So my diagnosis came right out of the blue – but then doesn’t it for pretty much all us.

I had my surgery pretty quickly followed by chemotherapy and then radiotherapy. It took about 10 months in all and I was very surprised at how much piling on the weight and having no hair affected my self confidence. But, it wasn’t as bad as I’d imagined beforehand and if I had to, I would do it all again. I had my biggest emotional wobble around the time my treatment was coming to an end and had some counselling through Tenovus, which I found really helpful. This coincided with Tenovus looking to start a breast cancer support group. So I volunteered to get involved and help get the group going.

I really wanted to meet and talk with other women going through the same thing. I always say that the biggest single thing that has helped me come to grips with my diagnosis is the support that I have had (and given) through meeting others. Although we are all different, and have our own unique perspectives of our experiences, I have found that the very act of sharing and talking about them has helped me enormously.

So, I’ve been involved in running the group since the beginning. I took over from Jane Brookes, our founding chairperson, when she was diagnosed with secondary breast cancer. This highlighted for me the unmet needs of people with secondary breast cancer. I promised Jane that I would do my best to keep the group going and I hope that I have kept that promise. I am also a Breast Cancer Care volunteer – something else that I really love and find immensely satisfying. Outside of that I work full time as a lawyer specialising in employment law and have a lovely husband and son (now 16 and several inches taller than me) who, when all is said and done, are the real centre of my life. I also have some great friends who make me laugh and I should try and see more often. In my spare time, I love holidays to far flung places (I’m hoping to get to Russia this year) and I am always in the middle of a good book. All in all life is pretty good – but I do need to work out how to fit some regular exercise in as well...any ideas anyone?

If you would like to be our next Breastfriends Personality (perhaps someone from the group or our wider community), let us know!

BREAST CANCER CARE YOUNGER WOMEN’S FORUM

Would you like to meet up with other younger women to share your experiences, get your questions answered about the medical management of breast cancer in younger women, and find out how healthy eating and exercise can benefit you?

Breast Cancer Care’s Younger Women’s Forums are designed to do all these things and more.

Forums are open to anyone aged 20-45 who has been diagnosed with primary breast cancer within the last three years. The two-day programme of talks, workshops and social time, including all meals and accommodation, is completely free of charge.

How do I book?
To see if this course is right for you, please contact us on 0845 077 1893. For more information contact the Specialist Services team.

Upcoming dates:
20-21 May 2011 - Manchester
1-2 Jul 2011 -London
16-17 Sep 2011 -Bristol
12-13 Nov 2011 -Birmingham

Would you like to meet up with other younger women to share your experiences?
## Breastfriends Cardiff and Vale Breast Cancer Support Group

### Meetings coming up in the next few months...

<table>
<thead>
<tr>
<th>Day and Date</th>
<th>Time &amp; Place</th>
<th>Speaker</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friday 8 April</td>
<td>1-3pm Cardiff</td>
<td>Helen McGarrigle Breast Care Nurse</td>
<td>Our fun Easter Egg Raffle and a talk about the new Breast Care unit at Llandough. Please bring chocolate contributions!!</td>
</tr>
<tr>
<td>Friday 15 April</td>
<td>2-4 pm Barry</td>
<td>Jayne Poynter Group Member</td>
<td>Jayne tells us all about her Kilimanjaro adventure</td>
</tr>
<tr>
<td>Monday 18 April</td>
<td>7-9 pm, M &amp; S Culverhouse Cross, Cardiff</td>
<td>Marks &amp; Spencer Lingerie Evening</td>
<td>The Culverhouse Cross store host a special evening for us</td>
</tr>
<tr>
<td>Friday 13 May</td>
<td>1-3 pm Cardiff</td>
<td>Kate Baker</td>
<td>Exercises following breast surgery</td>
</tr>
<tr>
<td>Tuesday 23 May</td>
<td>7-9pm Cardiff</td>
<td>Nicky West, Consultant Breast Care Nurse</td>
<td>Breast Reconstruction</td>
</tr>
<tr>
<td>Friday 27 May*</td>
<td>2-4pm Barry</td>
<td>Genetics Sian Nesbitt</td>
<td>Talk and discussion on the issue of genetics in relation to breast cancer *NB—4th Friday of the month!</td>
</tr>
<tr>
<td>Friday 10 June</td>
<td>1-3pm Cardiff</td>
<td>Melanie Doel ex-BBC presenter &amp; Breast Cancer Care volunteer</td>
<td>Experience of working for the BBC</td>
</tr>
<tr>
<td>Monday 27 June</td>
<td>7-9pm Cardiff</td>
<td>Dr Annabel Borley Consultant Clinical Oncologist</td>
<td>Strawberry Tea and breast cancer treatments update</td>
</tr>
<tr>
<td>Friday 17 June</td>
<td>2-4pm Barry</td>
<td>Anne Broekstra</td>
<td>Healing properties of aloe vera</td>
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<tr>
<td>Friday 8 July</td>
<td>1-3pm Cardiff</td>
<td>Ann Donald Group Member</td>
<td>Living and breast cancer care in Cyprus</td>
</tr>
<tr>
<td>Friday 15 July</td>
<td>2-4pm Barry</td>
<td>Jan Dell, The Haven</td>
<td>Talk about the services offered to breast cancer patients at the Haven in Hereford</td>
</tr>
<tr>
<td>Monday 25 July</td>
<td>7-9pm Cardiff</td>
<td>TBC</td>
<td>TBC</td>
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<tr>
<td>Friday 19 August</td>
<td>2-4pm Barry</td>
<td>No speaker</td>
<td>Chat and share tips and experiences</td>
</tr>
</tbody>
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**Cardiff Meetings** - take place in Rhiwbina, North Cardiff at the Margaret Whittaker Lounge. It is on the crossroads between Heol-y-Deri and Beulah Road on the same side of Heol Y Deri as the Spar.

**Barry Meetings** - take place in the Philip John room in the central Library, King Square, Barry.

### CONTACT US:

Phone: messages care of Breast Cancer Care Cymru on 0845 077 1894 or for Barry meetings call Pam on 01446 413886

Email: info@breastfriendscandv.org.uk
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Write: PO Box 4339, Cardiff CF14 8HA

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Breastfriends Cardiff and Vale are very grateful to Geldards LLP for helping us with the costs of distributing this newsletter.