EDI News
Newsletter of the Irish Breast Cancer Campaign
NO. 10_WINTER/SPRING_2008/2009
www.europadonnaireland.ie

Vision
That women of all ages in Ireland will know what they can and should expect in terms of risk, diagnosis, treatment, recovery and support in order to improve early detection rates and survival rates.

Your risk doesn’t stop at 65!
“ For some time it has been known that population screening for breast cancer only works and starts to show results, when it is offered with high quality specialist breast disease services. By the end of 2009, our national population screening programme - BreastCheck - will have a presence in every county in Ireland. And by the end of 2009, we will also be well on the way to having 8 specialist breast centres in place.

The vision and tenacity of Minister Harney in pushing ahead the cancer agenda and securing the services of Professor Tom Keane to lead the National Cancer Control Programme and the implementation of Ireland’s network of specialist cancer centres cannot be underestimated and we now, for the first time, have the opportunity to make substantial gains in reducing the number of deaths among women due to breast cancer in Ireland.

The current prioritising of breast cancer services in Ireland’s network of Specialist Cancer Centres means that breast cancer is paving the way forward for the safe and comprehensive transfer of other cancer services, with appropriate attention to standards, resources, communications with all stakeholders and quality assurance. Not surprisingly, it is the voices of women that have been instrumental in pushing for change including the voices of women, sadly no longer with us, who fell victim to outmoded practices and failure to benefit from the best that medical science has to offer.

While we are on the right road, changes of this magnitude take time. But the direction is clear and unequivocal and the momentum must not be lost despite the economic downturn.

And yet there are still many challenges. BreastCheck stops at age 64 for women, despite the evidence that risk continues and increases for women as they age. Three quarters of breast cancers are found in women over 50 and while the cumulative risk of a woman developing breast cancer before the age of 50 is one in 48, before the age of 65 it is 1 in 16, and by 75 it is 1 in 11. Clearly, the implications are that screening must continue for women into their 70’s and women have to make their voices heard and insist on staying in the screening programme.

EUROPA DONNA’s inaugural Breast Health Day was launched on 15th October 2008, in Milan and heralds renewed focus on what women can do themselves to reduce their risk of getting breast cancer. In this year’s newsletter you will find the key breast health messages every woman should know.

We are delighted to welcome Sarah Gillespie, EDI’s new part-time admin support.

This year’s AGM will be followed with a talk / discussion by Dr. Ailis Ni Riain on the topic of Follow-up which will be of particular interest to all members. We look forward to seeing as many of you as possible on Saturday, the 23rd of May, 2009, in Buswell’s Hotel.

Christine Murphy-Whyte
Chairperson EDI

EDI Chairperson elected Vice President EUROPA DONNA – The European Breast Cancer Coalition
We are delighted to announce that Christine Murphy-Whyte, Chairperson of Europa Donna Ireland, has been elected as Vice President of EUROPA DONNA – The European Breast Cancer Coalition. Christine has already made a very valuable contribution to the ED Board and to European advocacy and will continue to do so.

CONGRATULATIONS CHRISTINE!
Our Mission is to bring the voice of the woman with experience of breast cancer

- to raising awareness of the need for screening and access for all women to best quality specialist centres and

- to campaign for evidence-based, best practice health policy changes to ensure this happens.

Committee 2008-2009

Chair: Christine Murphy-Whyte
Vice Chair: Deirdre O’Connell
Secretary: Marie Ennis
Treasurer: Trudy Doyle
Members: Mary O’Brien, Sarah Tierney, Betty Watson, Dympna Watson
Information/Support Administrator: Sarah Gillespie

Thanks to sponsors, etc

Lisa Fitzpatrick, Donal Tierney, Q4, Red Dog, 54 Degrees, Trulife, National Lottery, Avon Breast Cancer Campaign, Fashion Targets Breast Cancer, GSK, Bristol Myers Squibb, Pfizer Oncology, Lilly, Astra Zeneca, Roche, Novartis Oncology, Staff of Anglo Irish Bank

It is our policy to provide our publications, conferences and information sessions free of charge so we welcome donations to enable us to continue to make information about breast cancer accessible to all women in Ireland.

Date for Your Diary /
AGM 2009 and Information Session /
Saturday 23 May 2009, Buswells Hotel, Dublin 2.

The Annual General Meeting of Europa Donna Ireland will be held on Saturday 23 May at 12 noon. As usual the AGM will be followed by an Information Session and we are delighted to have Dr Ailís Ní Riain, Irish College of General Practitioners, to speak on the topic of Follow-Up, followed by discussion.

For more details see our website www.europadonnaireland.ie
To register for Information session, please phone 01-4960198
The 2008 EDI AGM was held on Saturday 10 May in Buswell’s Hotel and included the Chairperson’s report, Treasurer’s report and a report of EUROPA DONNA European activities. Two new members were elected to the Committee, Trudy Doyle and Mary O’Brien - welcome additions to the team! Christine Murphy Whyte, Chairperson, thanked those leaving the Committee - Alison Sainsbury, who made a huge contribution to EDI over a number of years, including a stint as Treasurer, and Dr Maeve Pomeroy, whom we hope will be a source of professional advice in the future.

The business of the AGM was followed by an Information Session.

Mary Ivers, UCD Psychology Department, spoke about her research into cancer survivorship:

The CANSurvivor Project: what are the health service needs of post-treatment cancer survivors?

Naomi Fitzgibbon, Action Breast Cancer and Sarah Tierney

The CANSurvivor Project investigated factors impacting on the quality of life of post-treatment cancer survivors in the HSE East Coast area. The Project took a survey and workshop approach and then developed a pilot for the first evidence-based cancer rehabilitation programme in Ireland. Her findings certainly struck a chord with the audience and we hope that the success of the pilot will result in similar programmes being made available all over Ireland.


This covered practical issues such as social welfare claims, medical cards and tax claims. Dympna ended by stressing:

- Don’t make assumptions about what you are entitled to claim.
- Ask, Apply and Appeal your case if necessary!

For further information on these presentations, please do contact us at info@europadonnaireland.ie
Getting Key Messages to all Women

Following on our successful proposal to the National Lottery (reported on in EDI News 9) we are continuing to roll out our information programme. We are doing this through collaboration with DESSA (Disability Equality Specialist Support Agency) and our aim is to reach health, community and family resource networks with information regarding early detection (stressing the importance of screening) and treatment in specialist breast centres. We are developing Key Messages to use in the programme.

On 5 February EDI was part (with DESSA) of a meeting organised by Joanne Vance, Women’s Health Worker, NWCI - “What Women Need to Know about Irish Breast Cancer Services”. Both Christine Murphy-Whyte and Deirdre O’Connell spoke at the meeting, describing EDI and outlining our information project. Representatives from BreastCheck, the Women’s Health Council, and Action Breast Cancer, as well as from a number of women’s organisations and networks braved the icy weather to attend. We had a very useful discussion, giving us valuable feedback on a draft Key Messages document, and we continue to work on this.

Information/Support Administrator

In conjunction with our DESSA project we have appointed an Information/Support Administrator who works two days a week and is based in the DESSA office. Her name is Sarah Gillespie and she is very welcome. We have worked on a totally voluntary basis and without an office up to now and it makes a great difference to have Sarah. WELCOME SARAH! Sarah is doing a lot of work on membership (See below).

Membership

We have currently about 350 members in Ireland. In the past we used an Excel spreadsheet to keep our membership records up to date. With our expanded website and a related membership database system called CiviCRM, we hope to reorganise and streamline contact with all our members. To this end, I have contacted as many members as possible via email or post. As many members may have joined up to five years ago, their email or postal addresses may have changed. About 35 members have contacted me to renew their membership and more continue to come in.

I am now in the process of transferring our membership records onto the new system. Once this is completed, it will enable us to stay in better contact with our members as we can email all members or groups of members (for example “active” or “volunteer” members, or members who live in a particular area). It will also simplify membership payments with the system’s inbuilt automatic payment reminders, and will hopefully cut out unnecessary paperwork.

Anyone wishing to update their membership can contact me at info@europadonnaireland.ie and I will gladly forward an application form.

Sarah Gillespie, Information/Support Administrator

Website

As all our members may be aware, over the last year the Europa Donna Ireland website has been expanded and developed and we hope it will streamline and improve communications with all our members and the public in general.

We are constantly updating our website to include news, events and to provide links with other relevant websites. As EUROPA DONNA is a Europe wide organisation, our website can inform everyone of recent events and activities in other parts of Europe as they happen and we can do this by providing links on the website. For example, the “Short Guide to EU Guidelines” has been recently translated into a number of languages and we can let people know this and provide a link to the translations.

We will continue to update and improve the site in the future and will of course be putting up this and other newsletters on the website.

Deirdre O’Connell, Vice Chairperson
Sarah Gillespie, Information/Support Administrator
Academy Award nominee Minnie Driver arrived on the red carpet at Brown Thomas Dublin to launch Fashion Targets Breast Cancer Ireland Campaign 2008, in aid of Action Breast Cancer and Europa Donna Ireland. Minnie launched the Diane Von Furstenburg (DVF) designed yellow tote bag which was exclusively created for Brown Thomas to support this year's campaign. The bag was an instant hit and sold out in all stores in record time. Speaking about her trip to Ireland, Minnie commented “I was really honoured to be asked to participate in this year’s FTBC campaign in Ireland. It is such a worthy charity and a cause which is very close to my heart. We have all been touched in some way by breast cancer, it is important to raise awareness and help raise much needed monies to fight the battle. I am so proud to be associated with the campaign”

In October 2008 Orla Kiely launched a new accessories collection to support FTBC. Inspired by the iconic FTBC bull’s eye target symbol, the capsule collection features a graphic pattern in Orla’s signature style with the target symbol subtly worked in. “To have the opportunity to design a capsule accessories collection to communicate the importance of an issue close to all at Orla Kiely has been amazing. We hope to generate as much breast awareness as possible and that our design, which encapsulates the target logo, inspires hope and happiness to those who have been affected by breast cancer”, says Orla Kiely. The range was sold very successfully through Brown Thomas and is now sold out.

All proceeds from sales go to Action Breast Cancer and Europa Donna Ireland and funds are dedicated to campaigns for younger breast cancer sufferers. Plans for 2009 are already under way and another exciting campaign is taking shape. Thank you to all who supported FTBC in 2008 and we hope for your continued support in 2009!

Great Results from FTBC 2008 Campaign

Fashion Targets Breast Cancer comes together due to the hard work of a large team of people. A special thank you to the dedicated management and staff at Brown Thomas, especially Nigel Blow, Moira Murphy and Edel Kinane, for their continued support and enthusiasm. Thank you also to Clodagh Hogan, Caroline Kennedy and all at Kennedy PR for their outstanding work each year. All give freely of their time and their contribution is greatly appreciated by all at ABC and Europa Donna Ireland. Thank you to Naomi Fitzgibbon and all at the Irish Cancer Society who work with EDI on this great campaign.

Fashion Targets Breast Cancer (FTBC) began in 1994 as the U.S. fashion industry’s response to breast cancer - a widely recognized effort that raises public awareness and funds to support breast cancer research, education, screening and patient care. Inspired by Ralph Lauren in memory of his late friend Nina Hyde, The Washington Post columnist who died of breast cancer, the campaign became an ongoing initiative of the CFDA Foundations - the philanthropic division of the Council of Fashion Designers of America (CFDA), which represents over 300 of America’s leading fashion designers. Since its launch, Fashion Targets Breast Cancer has become the worldwide fashion community’s singular and most successful response to breast cancer - an issue of vital importance to its primary consumers: women.

Sarah Tierney, Committee Member.
Breast Health Day

Starting in 2008, ED declared 15 October as Breast Health Day, a day which is intended to disseminate information on breast health and raise awareness of prevention and early detection of breast cancer among women and girls across Europe. EUROPA DONNA launched a breast health website

www.breasthealthday.org

and you will find more information and see the activities of various ED member countries. Check out ED Switzerland! To mark the occasion, ED launched a comprehensive booklet: A Guide to Breast Health, which is available on the website and from info@europadonnaireland.ie.

EDI arranged a photo call on the day to highlight the importance of diet and exercise stating that "Appropriate lifestyle changes such as avoiding too much weight gain, increasing physical activity and eating a well-balanced diet where possible can reduce the risk of breast cancer. Studies show that excess body weight and physical inactivity account for approximately 25-33% of breast cancer cases."

A big thank you to Lisa Fitzpatrick who took time out of her busy schedule to promote World Breast Health Day as she really got the media attention!

Key Messages

- Living a healthy, active lifestyle, avoiding weight gain and obesity can help maintain healthy breasts. Studies show that about one-third of breast cancer cases can be attributed to increased weight and physical inactivity.

- Growing evidence supports that there is a protective association between physical activity and breast cancer, preferably over a lifetime, but probably beneficial even if begun after menopause.

- Women should limit their weight gain in adult life and maintain a body mass index (BMI) of 18.5-24.9. They should also try to limit their amount of abdominal fat. In women who have had breast cancer, maintaining a healthy weight may reduce the chances of recurrence.

- Engaging in moderate exercise for at least 30-60 minutes every day may help maintain breast health.

- Eating a well-balanced diet (with fat intake not exceeding 30%), including fresh fruit and vegetables in your daily food choices and limiting intake of red meat, has numerous health benefits.

- Limiting alcohol intake to one glass of wine or beer a day (10 grams of alcohol or less per day) can help keep breasts healthy.

- Having children at a younger age, having several and breast-feeding them also protects against breast cancer.

- Seriously considering the pros and cons of taking hormone replacement therapy and discussing them with your physician can influence future health.

- Mammography is widely accepted as the best method to detect breast cancer early.

- Participating in population-based mammography screening programmes can help detect potential problems early. Studies show that women who attend screening have a greater chance of surviving a breast cancer diagnosis.
BreastCheck finally rolled out in the West and South of Ireland during 2008 and will have moved into all counties by the end of 2009. In 2007 uptake by eligible women was 76.3%, a very good result by European standards but one which masks local variations. EDI hopes to address this issue over the next year by informing women country wide of the need for them to be screened and the importance of early diagnosis. We feel strongly that the programme should be extended to age 69, in accordance with the recommendations of the NCCP and the EC. This is backed up by good quantitative evidence. We will continue to campaign for this extension. BreastCheck now has screening promotion officers based around the country, for further information go to www.breastcheck.ie. EDI very much welcomes the development by BreastCheck of an excellent Guide to Screening for women with learning disabilities. Copies are available from BreastCheck.

Upcoming events

1. **Breast Health Day**
   - 15 October 2009
   - Will be celebrated by ED in Brussels. EDI will be planning an event for Ireland. Watch out for details on our website.

2. **LIVESTRONG Global Cancer Summit**
   - Dublin 24-26 August 2009
   - Seeking Leaders in the Global Fight against Cancer, the Lance Armstrong Foundation is taking the fight against cancer worldwide with the LIVESTRONG Campaign. The Global Cancer Summit in Dublin will bring together world leaders, organisations and individuals in a high profile display of unity against cancer. For more information see www.livestrong.org. See also www.europadonnaireland.ie for links to the Campaign website.

   - A chance to hear experts from all over Europe and meet European women with experience of breast cancer from many countries, the ED Pan-European Conferences are always very interesting and enjoyable events. Watch our website for more information soon.

4. **EBCC-7 7th European Breast Cancer Conference**
   - Barcelona, 24 – 27 March 2010
   - Another great breast cancer conference, this combines scientific and medical information with sessions especially aimed at breast cancer advocates. For more information watch our website.

Inviting the Minister to open the Conference, EDI Chairperson, Christine Murphy-Whyte, referred to the shocking revelations of breast cancer errors and misdiagnosis over the last two years, since EDI’s first national conference. She emphasised the utmost importance and urgency of having Specialist Breast Centres in place for the diagnosis, treatment and follow-up of breast cancer, stating: ‘This is the theme of our Conference, this is your conference, women with experience of breast cancer either personally or through relatives, and friends.’ She highlighted the need for supportive care in the community and the contribution of advocacy to making breast cancer a trail blazer for cancer services in general.

Mary Harney, Minister for Health and Children, opening the Conference, spoke of the need to move ahead and implement the specialist breast centres. Her strong commitment to the centres and to best quality cancer care led into the first session: Progress and Plans for Specialist Breast Centres, which was addressed by two key players in the field, Professor Tom Keane, Interim Director, National Cancer Control Programme and Dr Tracey Cooper, Chief Executive Health Information and Quality Authority. Professor Keane updated the delegates on progress in establishing the centres, pointing out that Irish survival statistics are poor by European standards. Dr Tracey Cooper’s contribution – Maintaining Momentum – Assuring Improvements – covered the work of HIQA in supporting quality improvements in symptomatic breast disease services and HIQA’s plans for future development to ensure quality.

Professor Niall O’Higgins pointed out that, at the 2006 EDI conference, the mantra had been ‘We must do better – soon’ and he detailed the improvements that have been made and the direction that must be taken. He also told the conference about developments such as Intraoperative Radiotherapy and the biologically-based targeted therapies which will make the cancer journey significantly easier on patients than it is at present.

Mary Murray, Advanced Nurse Practitioner, spoke about the emergence of a new type of nurse led follow up clinic, such as the clinic she runs in St Vincent’s Hospital, emphasising the holistic approach taken in responding to women’s needs in such clinics.

EDI was delighted to have as a key note speaker Judy Caldwell, Founder of the Canadian Breast Cancer Foundation British Columbia/Yukon region. Judy described her journey from diagnosis with breast cancer 15 years ago to an impressive range of patient advocacy initiatives: ranging from the foundation of the British Columbia/Yukon branch of the CBCF around her kitchen table to her presentation to the Canadian All-Party Women’s Caucus, including her dragon boat initiative and the use of innovative advertising to improving women’s attendance at screening. Her indefatigable...
and inspiring contribution to breast cancer advocacy recently focussed on a round-table event to which leading experts, clinicians, advocates and patients were invited and resulted in the landmark initiative: Towards a Future without Breast Cancer.

**Tina McGrath**, occupational therapist and breast cancer survivor, gave a fascinating talk on the preliminary results of her qualitative study of breast cancer survivors – Living to Tell the Tale – which uses storytelling to explore occupational biographies. Informed by her personal experience and seeing a cancer diagnosis as occupational disruption, this paper struck a chord with many women at the conference.

**EDI chairperson, Christine Murphy Whyte**, (also ED Board member and Treasurer) presented the work of EUROPA DONNA – The European Breast Cancer Coalition and of Europa Donna Ireland in her paper Joining Voices, Meeting Needs in Ireland and Europe. Christine highlighted the establishment of Breast Health Day on 15 October as an annual event and the need to deliver messages on a healthy lifestyle as well as those on best diagnostic and treatment practices.

An analysis of the evaluation forms shows that overall there was great satisfaction with the conference. The day was, on the whole, a very positive day, with participants fully engaged in the discussion. Topics requested for inclusion in future conferences included psycho-oncology and lymphoedema.

Thanks to all who helped including the excellent chairpersons for each session – Dr Janice Walshe, Veronica O’Leary, and Senator Frances Fitzgerald.

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**EBCC 6 Berlin 15 – 19 April 2008**

Together We Will Make The Difference

The 6th European Breast Cancer Conference was held in Berlin in April 2008, with the theme Together We Will Make The Difference. The European Breast Cancer Conference, held every two years, brings together the voices of doctors, researchers, nurses and patients, and is the only conference of its kind to bring together advocacy groups and major breast cancer institutions in one arena.

5,700 breast cancer specialists and advocates attended the conference hosted by EUROPA DONNA – The European Breast Cancer Coalition, EORTC (European Organisation for Research and Treatment of Cancer) and EUSOMA (European Society of Mastology), where they heard the latest findings on drug therapy, imaging, molecular targeting, managing special patient populations, lifestyle factors, survivorship, screening and implementation of specialist breast units.

Throughout the conference, EUROPA DONNA teaching sessions and wrap-up sessions summarised and simplified key findings presented and were attended by numerous advocates as well as professionals. EDI Chairperson, Christine Murphy-Whyte, opened a most interesting symposium on lifestyle and survival after treatment for breast cancer, by posing the questions: “What breast cancer survivors want to know about lifestyle after breast cancer” which were in turn answered by a range of experts. To see the statement issued by Ingrid Kössler, President of EUROPA DONNA, see the Conference report on our website www.europadonnaireland.ie

**EUROPA DONNA chooses short film as Nathwani prize winner**

ED President Ingrid Kossler awarded Gabriele Scharer of Switzerland the Nathwani prize for her short film “Busenfreundinner/Affaires de Bain”, which is a subtle emotional portrayal of two friends who meet at a swimming pool and their different approaches to communicating about the disease. Of the many nominations, EUROPA DONNA chose this short film as the winner because “this film conveys a unique message that everyone needs to understand and can provide a special tool that could be used in developing communication skills for health professionals and members of the breast cancer multidisciplinary team as well as patients, their families and friends.”

For the first time, EUROPA DONNA was responsible for collecting the Nathwani prize nominations and electing the winner for later approval by the EBCC Board. The prize is awarded at each EBCC to an individual who has made a difference in breast cancer through a cultural or artistic medium.
Become a more effective breast cancer advocate: EUROPA DONNA’s Advocacy Training Programme.

Following the pilot programme launched in 2001 EUROPA DONNA - The European Breast Cancer Coalition, offers an annual European Breast Cancer Advocacy Training Course in Palazzo delle Stelline, Milan, Italy.

The course takes 2.5 days and is open to 2 participants from each of Europa Donna’s 42 member countries, who are nominated by their ED National Representative. In November 2008 Europa Donna Ireland nominated Trudy Doyle and Mary O’Brien to attend the Advocacy Training Course.

The course covered various areas of importance to breast cancer advocates including diagnosis and treatment of breast cancer, to learning effective communication and public speaking skills, lobbying techniques and media training. The opening module this year was given by Alberto Costa, MD, Director of European School of oncology, Milan and Head of Breast Unit, Maugeri Foundation, Pavia, Canton Ticino, Switzerland. He addressed basic biology of breast cancer and genetics.

Dr Eva Negri, Sc. D. Head of the Unit of Epidemiologic Methods, Istituto di Ricerche Farmacologiche “Mario Negri”, Milan, spoke on Epidemiology, Prevention and Risk Factors.

Dr Olivia Pagani, Institute of Oncology of Southern Switzerland, co-president of the breast cancer project group of the Swiss Institute of Applied Cancer Research (SAKK), spoke on clinical trials confirming that they should address women’s well being and safety.

Dr Marco Rosselli Del Turco, President of European Society of Breast Cancer Specialists (EUSOMA), emphasised that early detection, obtained by means of population based mammography screening, but also by promoting self awareness and providing high quality diagnostic services, significantly reduces breast cancer mortality.

The second day was a communication skills programme designed to equip the participants with strong advocacy skills. Such skills included the ability to present in public, the ability to make your case assertively, building constructive relationships with the media and engaging in effective political lobbying.

All in all the weekend was intensive but gave all the 46 participants from 23 countries an opportunity to view the bigger picture of the work of an advocate. Everyone seemed to enjoy the experience and there were many laughs and story swapping when we did take time out for a cup of tea and an enjoyable meal in the evening.

For a more detailed account of the Training Programme, please see our website www.europadonnaireland.ie

Mary O’Brien

A Short Guide to the EU Guidelines now available in several languages

The European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis (4th edition 2006) are key to enabling EUROPA DONNA to achieve its mission for the benefit of all women across Europe. The Guidelines set the standards for mammography screening, diagnosis, and specialist breast units. In October 2007 ED published a Short Guide to the 4th edition of the Guidelines – which is a fundamental tool for ED advocates across Europe. The Short Guide has now been translated into Italian, French, Spanish, Turkish and Swedish and this year it will become available in German, Russian, Polish, Greek, and Slovenian. Dutch and Georgian translations are also in the works. Copies of the Guide, in all the languages, can be downloaded from www.europadonna.org.
Join us... see overleaf
Join Us, Support Us, Campaign for Change

Please complete (in BLOCK CAPITALS) and return this membership form to Europa Donna Ireland, P.O.Box 6602, Dublin 8. If you have any queries, ring 01 496 0198 or email edi@iol.ie. You can also join up via our website www.europadonnaireland.ie

Name: ____________________________________________________________

Address: __________________________________________________________

____________________________________________________________________

Tel: ________________________________________________________________

email: _____________________________________________________________

Are you interested in being actively involved in our campaign? Yes ☐ No ☐

I enclose annual membership fee €15 Cash ☐ Cheque ☐ Standing Order ☐

Bank and Branch: _______________________________________________________

Account no: ____________________ Sort code: _____________________________

I hereby authorise the above Bank to pay the annual fee to Europa Donna Ireland account in Bank of Ireland, 85 James's St., Dublin 8, starting

Starting from (date) ____________

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Signature: __________________________________________________________

Date: __________________________________________________________________