

Record of the Suffolk West Federation Resolution Conference 29th April 2021 (held via Zoom)

This year the meeting was held via Zoom due to COVID 19 restrictions and took the form of two sessions.

Session 1 @ 2.30pm (25 members present)

Sue Beavan (retiring Chairman of MAC committee), welcomed everyone far and near and introduced the speaker John Lynch, who is an Ovarian Cancer Action Ambassador. The wording of the resolution was read out.

John explained that Ovarian Cancer Action exists to prevent women dying of Ovarian Cancer, currently one every two hours. By funding research and by campaigning they seek to ensure that women and healthcare providers know the risk factors, the signs and symptoms and the treatment options and can be enabled for women to take informed and rapid action. John's very clear power point presentation gave us many sombre facts and figures. We learned that the UK lags behind even some parts of Europe with a lower 5 year survival rate. Ovarian Cancer Action seeks to reach the general public, women specifically, and interestingly enough the men in their lives, who can play a crucial supporting role. He said "improve awareness-improve survival". The corona virus has impacted not only on reduced funding to proceed with research but with reduced face to face consultations, so fuelling an increase in late diagnosis which is the always major problem with this disease. Its subtle symptoms are easily confused with other more common complaints like IBS and thus 50% of patients present at the late Stage 3 or 4 when survival rates are low.

We learned there are three types of ovarian cancer and that it is most often found in over 50s but sometimes in just random cases at any age. The four symptoms John highlighted were persistent bloating and considerable stomach pain, a struggle with eating and frequent need to wee. If any of these are severe, persistent, frequent, out of the ordinary or have no obvious explanation, a doctor should be consulted and CA125 blood test requested, followed perhaps by an ultrasound examination. John urged us to get to know our bodies! Sometimes women are busy looking after families and neglect to look after themselves. It also became clear that family histories are crucial as there is a genetic cause in many cases, passed on through generations. One in 400 carry the BRCA gene often associated with breast cancer or a similar 'Lynch' mutation gene. There is a 50% chance of passing this on to the next generation.

John had experience around this in his family and his quiet competent delivery was full of good advice.

John's talk covered the subject so thoroughly that there were few questions or comments. John recommended the Ovarian Cancer Action website for more information including a tick box diary of symptoms which could be filled in prior to a consultation to aid discussion of symptoms. John was warmly thanked for his thoroughly comprehensive talk.

It was agreed that there was little that could be said against the resolution other than that a number of charities were already working in this field, which could be either a point in favour as indicating ready partners or a point against as indicating a subject already under enough control.

Sue Beavan then explained the current voting procedure via the seven link delegates with votes for and against only this year, to be in to your designated delegate by 9th July.

Sue then introduced Annie Phillips, (Vice chair of Public Affairs committee) who gave a swift and enthusiastic history of WI resolutions and mandates past and present. She highlighted the relevance of some past campaigns to modern life and noted the wide range of topics including a number from WIs in Suffolk West.

Thanks were expressed to all attendees and contributors and to Sue Beavan, Brenda Dyer and Maggie Glavin for their technical input, together with Gwen Williams (Chair PA committee) and to Val Simpson (PA) for sourcing speakers for the day.

Session 2 @7.30pm          38 members were welcomed to the meeting.

Brenda Dyer (Vice Chair MAC) welcomed everyone and introduced the speakers for the evening Ruth Griggs and Sue Stockholm.

The wording of the resolution was read out.

Ruth began by explaining that Ovacome was a charity founded 25 years ago to support and inform anyone affected by ovarian cancer including families and friends. It is a membership

charity and some of their trustees have remained on the Board since its foundation in 1996. She expressed great pleasure that the WI should take an interest in this topic and join their campaign. Ruth introduced Sue Stockholm, who, like other Ovacom volunteers, would share her story with us and help put the facts and figures into a more human context.

Ruth began her talk by saying that Ovarian cancer is not a common cancer. It carries a 1 in 52 risk, while breast cancer carries a 1 in 7 risk, but as there is no screening or specific diagnostic test, health providers rely on recognising it from subtle symptoms and a GP probably sees only one case every five years. It is, however, a deadly disease and many patients present too late for effective cure and face living with the illness. To combat the significant number of lives lost, Ovacom have introduced a BEAT campaign linked to recognising the symptoms that might save lives.

- B is for bloating
- E is for eating
- A is for abdominal pain
- T is for toilet.

She showed us some neat cards to publicise this BEAT campaign. Finally, Ruth described some factors that increase risk such as age and family history. Interestingly the contraceptive pill acts as a protective factor, while not having children sends the risk up. She pointed out too that both Mum and Dad might pass on the faulty gene. She urged us as the expert on our own bodies to be firm and confident in consultations and feel able to talk about all symptoms. Ovacom are seeking more GP training so that a trained specialist nurse or doctor could be available in every surgery to spot symptoms. Finally, Ruth was keen to explode the myth that a cervical smear test would reveal ovarian cancer.

Ruth introduced Sue Stockholm who bravely recounted, in some detail, the story of her diagnosis and treatment so far. She described her classic symptoms and of course this immediate personal input made a great impact on her listening audience, who could not but be full of sympathy for what was a difficult and on-going story. We heard how her CA125 test instead of registering a normal 35 rose to 8,000 at one point. She described coping with family life and losing her hair through chemotherapy. Her treatment involved a colonoscopy and a very painful biopsy before a trial with infusions every two weeks. She said how she

valued the community groups of cancer survivors who meet to support each other. The meeting admired her spirit.

Sue was a great advertisement for Ovacome's work and wide support services which also include things like leaflet translations into foreign languages. Ruth explained that they run a free phone help line available to all affected by ovarian cancer, both families, friends and colleagues. Research trials indicate that new immunotherapy may improve treatments giving hope for the future.

Both speakers were thanked. There were no questions and few comments. Perhaps the nature of the talks will prompt more discussion later in WI meetings to come. It was pointed out that little could be said against the motion except that it was an ongoing problem that several charities already seek to address. However, Ruth made a point of welcoming WI involvement in their work.

In a change of mood, Annie Phillips then gave a resume of WI mandates and resolutions down the years showing a amazing variety of subjects, many of them relevant today. She noted the recent funding to improve cervical screening in Suffolk with the appointment of four nurses had come following the campaign "Five minutes that matter" to increase awareness of cervical screening.

Sue Beavan (MAC committee) then explained the current voting procedure via the seven link delegates, with votes for and against only this year, to be in to your designated delegate by 9th July.

Brenda Dyer thanked everyone attending and in particular members of the P.A./MAC committees team Sue Beavan, Maggie Glavin, Gwen Williams, Annie Phillips & Val Simpson, who between them sourced the speakers & ran the technology to enable the meeting, the first resolution conference of this kind in Suffolk West.

Jill Newell