PEOPLE BEFORE PROFIT
SOCIALISM FOR THE 21ST CENTURY

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Breast cancer in women accounts for around 30% of all invasive cancers for women with around 3,000 cases a year. Ireland had the 8th highest incidence rate and 5th highest mortality rate for female breast cancer in the EU in 2020.[1]

The following table is the data for the incidence of Brest Cancer for 2015 taken from the website of the National Cancer Registry Ireland (NCRI):

Breast Cancer Incidence (Women) 2015				
Age	N of Cases	% of Cases	% of all Invasive Cancers	Crude Rate per 100,000
25_29	16	1%	14.55%	10.67
30_34	46	1%	25.14%	24.07
35_39	141	5%	44.62%	74.22
40_44	200	6%	45.56%	112.79
45_49	316	10%	46.81%	197.62
50_54	473	15%	52.79%	315.8
55_59	399	13%	40.14%	304.53
60_64	411	13%	35.22%	352.95
65_69	258	8%	21.18%	252.28
70_74	282	9%	23.10%	369.17
75_79	222	7%	20.57%	374.78
80_84	186	6%	21.73%	424.02
85+	144	5%	16.76%	328.92
Age Band	3094			
Band 0_49	719	23%	38.49%	44.27
Band 50_64	1283	41%	41.97%	322.97
Band 65_74	540	17%	22.14%	302.26
Band 75+	552	18%	19.76%	375.82

[11] https://ecis.jrc.ec.europa.eu/

Women were screened for breast cancer from the ages of 50 to 64 until 2018. This has been extended to 69 since then. It can be seen above that 41% of cases were in the 50 to 64 age band. If the band is extended to 69, 49% of cases are accounted for.

Almost a quarter of cases occur in women under 50 and therefore outside the screening process. In 2015 that was 719 women. It is worth noting that these cases account for just over 38% of all invasive cancers for women under 50. Taking women between 35 and 50 breast cancer accounts for 45% of all cancers. It can also be noted that over 200 cases were in women under 40, 7% of all cases.

This is in line with data for the period 1994 to 2016 collected by the NCRI and published as Cancer Trends 37.[2]

Clearly, the incidence and risk of breast cancer increase with age. Between 1994 and 2016 the median age for diagnosis was 59. As in 2015, 40% of cases were diagnosed between 50 and 64.

But the following should be noted:

1. For women younger than 50, rates increased by, on average, 1% per year across the whole period, from 34.2 per 100,000 in 1994 to 45.1 per 100,000 in 2016.
2. **The percentage of younger women with a late-stage (III or IV) diagnosis increased from 18% in 1994-1999 to 22% in 2008- 2015.** The percentage with a stage I diagnosis increased from 22% to 26% while the percentage with a stage II diagnosis decreased from 53% to 48%.
3. In contrast, **there was a large increase in the percentage presenting with stage I cancer for women in the screening age-group (50-64 years),** from 23% in 1994-1999 to 44% in 2008-2015. The percentage with a stage II diagnosis showed a related but not as steep decline, from 50% to 38%. The percentage of late-stage cancer declined from 20% in the earlier period to 16% in 2008– 2015.
4. As NCRI say “This suggests that there has been some stage replacement in the women who are eligible for screening”.
5. It is concerning to note that the rate of increase in late-stage breast cancer was 2.4% per year for younger women whole the rate for women in the screening age band was 0.4%.
6. Substantial improvements in survival are also evident for each age-group. However, the extent of the improvement, comparing diagnosis period 2011-2015 with 1994-1999, has **been highest for the screening-eligible age-group (50-64).** For this age-group, the survival improvement is equivalent to an average reduction in five-year mortality risk by about 70%, compared with a 55% reduction in the mortality risk in the under-50 group and a 40% reduction in the 65+ group.

[2] https://www.ncri.ie/sites/ncri/files/pubs/Trendsreport_Breastcancer_20191107_0.pdf

Screening in the Wider Context

According to the OECD[3]

- Breast cancer is the most frequent cancer among women across EU countries, with more than 400, 000 cases diagnosed each year across EU countries;
- On average across EU countries, the proportion of screened women increased from 54% to 58% between 2006 and 2016;
- Breast cancer survival reflects early diagnosis as well as an effective treatment. All Western European countries have attained five-year net survival of at least 80%:
- WHO now recommends organised population-based mammography screening for women aged between 50 and 69 in EU countries, if specific criteria are met such as whether women can make an informed decision based on the benefits and risks of mammography screening.
- There is a debate about whether screening is appropriate for women under 50 but some European do screen under this age[4]. They include Austria, Greece, Hungary, Iceland, Slovakia and Portugal. Sweden has different ages for different regions.

Sweden as an example of early screening

In Sweden, breast cancer is the most common cause of death in women 50 years and under. There's a symptom-free period when cancer is developing. In women aged 40-49, this period is 2.4 years.

In Sweden screening is offered every 18-24 months. Some regions offer screening every 18 months for younger women because the breasts are tighter and, while it's less common, cancer often progresses faster.

In ages 40-49 the death rate is reduced by 16% where screening is introduced.[5] In regions in Sweden where screening was introduced for 40-49 year-olds the death rate reduced by 26% compared to regions that didn't. [6]

Women Under 40

It is argued that screening is not appropriate for women under 40 as most have dense breast tissue that prevents routine mammograms from being a useful screening tool. But compared to older women, young women generally face more aggressive cancers and lower survival rates. More and more evidence tells us that breast cancer before age 40 differs biologically from cancer faced by older women.[7]

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[3] OECD/European Union (2018), "Screening, survival and mortality for breast cancer", in Health at a Glance: Europe 2018: State of Health in the EU Cycle, OECD Publishing, Paris/European Union, Brussels. DOI: https://doi.org/10.1787/health_glance_eur-2018-42-en

[4] https://www.karger.com/Article/Pdf/503715

[5] Gotzsche, PC, Nielsen, M. Screening for breast cancer with mammography. Cochrane database of systematic reviews (Online). 2011; (1):CD001877.

[6] Hellquist, BN, Duffy, SW, Abdsaleh, S, Bjorneld, L, Bordas, P, Tabar, L, et al. Effectiveness of population-based service screening with mammography for women ages 40 to 49 years: evaluation of the Swedish Mammography Screening in Young Women (SCRY) cohort. Cancer. 2011; 117(4):714-22.

[7] For sources see https://www.youngsurvival.org/learn/about-breast-cancer/statistics

This makes a quick diagnosis important. According to the Marie Keating Foundation, for all ages, urgent referrals are seen within 2 weeks, early referrals will be seen within 6 weeks and routine referrals will be seen within 12 weeks as per the National Cancer Control Programme Guidelines. [8]

We have been presented with significant evidence that young are finding it hard to access early diagnosis (see cases 1and 2) and this is an issue that needs to be urgently addressed.

Young Women Argue for Early Screening

Case 1: It Takes Too Long To Get A Diagnosis

I found a lump in my breast accidentally in December 2018(I had not been doing any checks as I wasn't aware of a breast cancer risk at 29 with no family history). I attended my GP roughly 2 weeks later in January 2019 as I had noticed the lump did not go away. My GP referred me to the breast clinic in St. James hospital as a medium risk, which meant I should have been seen within a 2 to 8-week timeframe by the clinic.

I then received a letter from the breast clinic in St. James for an appointment in April 2019, which **was roughly 12 weeks or more after my initial presentation to my GP.** I attended the appointment in April and the doctor carried out a physical examination and told me the lump was benign. She said I would not be having any further tests today but that I would receive a letter in the post with an appointment for a scan so that they can find out what type of benign lump it was.

I received an appointment for a scan a couple of weeks later. The appointment was not until June 2019 **at least 8 weeks after my initial presentation to the breast clinic.** When I attended the breast clinic for my ultrasound in June, I was again told the lump was benign. They then told me that was all fine and almost let me leave without doing any more. It was only a last-minute decision that the radiographer then decided to biopsy it to in her words find out "what type of benign lump" it was as if it was a papilloma they sometimes like to remove these.

I was told to come back in a week for the results. It was the following week then that I received my diagnosis after being told time and again that the lump was benign and being left waiting more than 12 weeks for my first appointment and again a further 8+ weeks for a scan/biopsy.

Since my diagnosis, a few women I know who are 50+, have found lumps and been referred and seen within two weeks of referral, most of which have been benign but got triple assessment done on the one day and the couple that weren't had their diagnosis within 3-4 weeks of first attending their GP.

From the time I first attended my GP to my diagnosis, it was more than 6 months.

Luckily enough for me - although a grade 3 cancer it was not as aggressive as triple-negative or HER2 positive cancer (which are more aggressive and more likely to be found in younger women). However, my cancer had spread to one lymph node where they found a 6mm tumour - could this have been avoided if the cancer had been detected earlier? - I think quite possibly! Once the cancer spreads to your lymph nodes it affects your prognosis and also increases the likelihood of having to

[8] See https://www.mariekeating.ie/cancer-information/breast-cancer/diagnosing-breast-cancer/

undergo chemotherapy which may or may not have been able to be avoided had the cancer been contained to the breast.

My sister who lives in Australia attended her GP, after my diagnosis, to tell her, I had been diagnosed with breast cancer. The following day she received an ultrasound on her breast. How is it that Australia can carry out an ultrasound on a woman with no symptoms of breast cancer in one day, but in Ireland, it takes 6 months for this to happen?

I have done my own research and it does seem like 40 is the most realistic age for screening. However, from my experience in attending the day ward for chemotherapy, there were a number of women below 40 with a breast cancer diagnosis - what more can be done for all of the younger women?

I'd like to suggest that maybe there is a way that the government could look at bringing in a same day triple assessment policy when you are sent to the breast clinic, although in this instance I would have still been waiting 12 weeks - it would have cut out the further 8 weeks until my scan/biopsy.

There seems to be a real lack of awareness in younger women to their risk of breast cancer. I was wondering would it be possible that an awareness programme could be started up in schools for either 4th year or 6th-year students where an assembly is held to inform them of a risk of breast cancer at a younger age and also to show them how to check themselves properly. This might be something that can help women under 40 better detect a cancer themselves since it isn't likely that screening would be reduced lower than that. I don't know if that's possible to do - but I think it could be something that could help!

Case 2: It Takes Too Long and We Need Triple Testing

I'm 36 and I am currently living with incurable secondary breast cancer.

My story starts back in February 2018, I found a small lump in my breast through self-check - something I always done from a very young age. I ignored that lump as I thought I was too young, too fit, too healthy to get cancer. Plus, I was naive and uneducated, I thought breast cancer was an old ladies' disease.

I was 33. For 6 months I watch my breast change in shape, swell, my nipple started to invert before finally in August 2018 I went to my GP as I couldn't ignore it any longer.

My GP was extremely kind, because of lack of family history, my age and fitness level he thought it was nothing more than a cyst but offered, thankfully to refer me to the breast clinic. I was extremely anxious at the thoughts of this, I had to sign off work sick to try and muddle through my anxiety and my GP marked my referral as urgent.

I waited 10 weeks for my appointment. An urgent appointment that took 10 weeks. I firmly believe that I was just written on paper to be a fit and healthy young person and no cause for concern.

At this appointment on the 18th of October 2018, I had a triple assessment, 2 weeks after my 34th birthday. A physical exam followed by a mammogram (eventually) and a biopsy. I say eventually because when I arrived at that department I was told that because I was under 35 they wouldn't mammogram me and I was sent for an ultrasound instead and immediately sent for a mammogram before having the biopsy done.

It was at this appointment that the consultant could see on my ultrasound that there was cancer in my breast and my nodes in my armpit. I heard the words "too young " several times over the next while and I still hear them today.

I had 8 rounds of chemo, I had an unsuccessful lumpectomy followed by a single mastectomy with no reconstruction. I had 25 rounds of radiotherapy and was sent on my merry way given the all-clear with minimal chance of reoccurrence. I was never scanned to confirm the all-clear and I knew there was something wrong from the time I finished chemo in March 2019.

I subsequently developed cancer in my neck, spine and hip. At 35 I had to have a hip replacement to prevent my leg from breaking. I had to endure radiotherapy to my spine making me extremely nauseous. Radiation to my hip to sterilise the area and radiation to my neck resulting in hair loss again. After much pain, I was admitted to the hospital and it was diagnosed that I had fractured my c2 spine where the tumour had weakened the bone. I was in a neck brace for months and still have pain.

I take pain medication daily. I take a form of oral chemo, along with a monthly injection to keep my ovaries asleep putting me into a medical menopause and all the side effects that go with it.
I live every 3 months to every 3 months in between scans and hope and pray that every scan comes back stable. I can't fault the care I've had from the teams that have looked after me.

I just feel that if a referral has been sent that a triple assessment should be performed to rule out anything sinister. This should include a physical examination, a scan and a biopsy. And a final point, scans should be given at the end of treatment to confirm that the body is free of cancer. Had I had that maybe I would not be where I'm at now.

Genetic Testing for BRCA Mutations

A Country Profile for Ireland[9], published in 2019, in relation to this issue paint a fairly bleak picture of the situation here. It makes a number of key points:

1. There are no national data on the proportion of breast cancer cases that are due to BRCA mutations.
2. Based on international data, it is thought that most women have a 12.5% risk of developing breast cancer in their lifetime. This risk increases to 60–90% among women with a BRCA1 mutation and 45–85% among women with a BRCA2 mutation. Breast cancers related to BRCA1 mutations are more likely to be triple-negative breast cancer, which is difficult to treat.
3. There is **no comprehensive national policy on genetics and genetic testing in Ireland**, but there is a clear intention to scale-up access to these services. Further, there is a lack of data on BRCA-mutation carriers in Ireland, hampering the government's ability to make evidence-based policy decisions.
4. Ireland has established criteria for genetic testing for hereditary breast cancer, but these are more restrictive than in many other European countries. In contrast with many other European countries, Ireland does not make genetic testing available to all asymptomatic women at high risk of BRCA related breast cancer. The report says that the National Cancer Control Programme noted that, with the currently available resources, the introduction of testing for all women at high risk regardless of whether they are affected by cancer – as is practised in the UK – is not feasible.
5. Waiting times for an initial consultation, genetic testing and counselling are high, placing a burden on

[9] https://www.healthpolicypartnership.com/wp-content/uploads/Genetic_testing_for_BRCA_mutations_Ireland.pdf

people waiting for tests and **potentially delaying initiation of necessary treatment.**

6. Because of this, many woman choose private testing at a high cost of between €1400 and €1800 making this a barrier for many women.
7. Recommendations for surveillance of BRCA mutation carriers are in place but are not **implemented on a nationwide basis**. Recommendations include breast cancer surveillance for women with an identified genetic breast cancer mutation and **annual digital mammography for women aged 40–49 who have high familial risk but no identified genetic mutation.** To ensure equity of access, the HQIA suggests establishing an organised surveillance programme at a national level. The National Clinical Guideline for breast cancer provides recommendations for women with BRCA-related breast cancer, **but guidance for reducing breast cancer risk among asymptomatic BRCA-mutation carriers appears to be lacking. This may be contributing to low uptake of a preventive double mastectomy**. One study found that only 12% of asymptomatic BRCA-mutation carriers in Ireland decided to take up this surgery.
8. Ireland has a low level of provision for genetic counselling and GPs feel ill-equipped to discuss genetic testing with patients.

The report concludes

"National guidelines which support access to comprehensive care for BRCA-mutation carriers are urgently needed. Access to genetic testing services for those at high risk of BRCA-related breast cancer is severely hampered by restrictive eligibility criteria. Recommendations on surveillance are not being adopted and there are no national guidelines on risk-reducing options for women with BRCA mutations who do not yet have breast cancer."

Case 3 Brca2gene

I am 45 years old with a husband and 3 children. In 2017 I found out I had the Brca2gene, I was 43. It wasn't till then that I started receiving screening for breast cancer. I had a full hysterectomy in November that same year,

In May 2019 after 2 years of screening, I was diagnosed with breast cancer. I up to date I have had chemotherapy, radiation, and a double mastectomy.

If I had not been diagnosed with the Brca gene I would not have been getting screening and probably would never have caught my cancer in time. My cancer was found to be a small lump in my left breast, and on my right side, it was in my lymph nodes.

I would have never found it myself if it wasn't for screening, and it could have been much worse if it wasn't for screening.

I was very lucky in a sense as I am here to talk about it, I also have a sister who is 10 years younger than me. She also has the gene but she only gets ultrasounds and MRIs, no mammograms,

In my experience I really do think screening should be done earlier, as cancer does not care for age, women and men are getting it younger now.

Conclusion and Demands

In light of the evidence presented here PBP will campaign for:

1. Screening from 40;
2. Triple assessment for young women who present with possible breast cancer: the should include a physical examination, an MRI and a biopsy. Mammography is of limited added value in terms of cancer detection when breast MRI is available for women of all ages who are at increased risk.[10] There should be early referral for these tests.
3. Revision of criteria for access to genetic testing so that all women at high risk of BRCA related cancer have access to genetic testing and genetic counselling in the public health system.
4. A public-funded education programme in schools in relation to breast examination.

[10] see https://breast-cancer-research.biomedcentral.com/articles/10.1186/s13058-018-1019-6
And https://www.breastcancer.org/research-news/mri-twice-a-year-better-than-annual-mammo