

# I iest Tesch MP, Member for Gosford

Dealing with a cancer diagnosis is a lifeshattering experience for both patients and their loved ones - and every human response is different

Some people cry, others remain silent and some people may hear the words but refuse to believe them.

When my mum was diagnosed with breast cancer my list of questions was endless.

What stage was it? What were her treatment options? What were the right words to say to her?

But through that difficult time, I know the one thing that got Mum through her breast cancer diagnosis - was having my sister Trudii, a Gosford-hospital trained nurse, guide us every step of the way.

Through the multiple cycles of chemo, the radiation and the endless scans and blood tests. she was our Sherpa on Mt Everest, always asking the right questions, always providing a hand to squeeze and always saying exactly the right thing, handling every situation with empathy, practical-mindedness and compassion.

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Since Mum's initial diagnosis a decade ago, survival rates for breast cancer have improved exponentially. Today, the overall five-yearsurvival rate for breast cancer is over 90% and for early stage breast cancer 99%.

Nevertheless, more than 25,000 eligible Central Coast women did not attend screening mammograms in the past two years.

And with breast cancer rates 18% higher than the NSW average – we cannot be complacent.

Preventative health promotion, healthy lifestyle choices and education are very important to our regional community.

And that's what this compendium is all about - improving awareness, supporting the fighters and celebrating the survivors.

Denise's Story .....22

Yours Faithfully,

#### Liesl Tesch MP

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# Dr Mary Ling

**Breast and General Surgeon** 

In surgery, we don't remember days, we remember moments.

And there is nothing more heartwarming to see the smile on a patient's face when they have taken breast cancer head on - and won.

What's even more inspiring about these women, who have been prodded with more needles and endured more surgeries and scans than most people have had in a lifetime - is their courage and humour at a time when breast cancer has intruded into their lives.

I feel privileged to be part of The Central Coast Breast Cancer Compendium, which features stories written by Coastie women about their personal experience with breast cancer.

These women have shared their stories with the purpose of educating and informing, and offering hope - not just to the one in eight Aussie women who will develop breast cancer but also to family, friends and health care providers.



Many thanks to all the patients and medical professionals who have shared their wisdom in this compendium - together let's keep working towards world class breast cancer care on the Central Coast.

Yours Sincerely,

Dr Mary Ling



#### My Care Kit

My Care Kit is available free of charge to women who have undergone breast cancer surgery. It contains a specially designed Berlei bra and soft form(s). The bra



features inserts for soft forms, as well as extra hooks and eyes in the back to allow for swelling. It is designed to be worn after surgery and during radiation treatment.

#### **My Journey Online Tool**

Breast Cancer Network Australia's *My Journey* is the leading resource for women newly diagnosed with breast cancer.

From 2019, *My Journey* will be available in digital format with easy access via computer, tablet or smartphone. The online version allows women to access information and support tailored to their specific needs at all stages of their breast cancer journey (rather than a one-size-fits all approach of the past).

Go to bcna.org.au/myjourney to sign up.

# **Turning Heads...**

Want to dress in style after breast cancer?

Visit <u>pinkcollectivestyling.com</u> which showcases fabulous fashion with styling features suitable to the woman affected by breast cancer. The MY Style tab collates many flattering outfits with great necklines and helpful features to dress around an altered cleavage following mastectomy. The HER style tab showcases a different range of clothing suitable to the woman with unaffected cleavage who may have other imbalances as a result of breast cancer surgery.



# $Margaret\,Beardslee\,$ 60, OAM, Killarney Vale

For twice world age duathlon champion Margaret, there was never any chance of throwing in the towel after a cancer diagnosis in 2018, instead she used the towel to wipe the sweat off her face...

"Before my breast cancer diagnosis, I had just trained to my max for a bike race and was as fit as I had ever been – racing alongside those 30 years my junior. For me, life revolves around being active and fit.

During my cancer treatment, daily exercise kept me in good spirits. Being able to swim, ride and run allowed me to feel somewhat normal and hopeful that I could regain fitness after treatment had finished.

In the past, there was the notion that cancer patients needed to be wrapped up in cotton wool, stay in bed and avoid anything "too strenuous". But current research has shown that exercise is actually an important part of cancer treatment.

I exercised almost every day throughout chemo, even if it was just a 15-minute walk.

After each cycle of chemo, I would plan my daily workouts until the next treatment.

If it was a three-week cycle, I knew the first week would need to be easy walks or bike rides (just to feel the breeze).

By the third week I would try to pick up the pace or increase the distance to those workouts I was doing pre-treatment. baton bearer for the 2018
Gold Coast Commonwealth
Games after undergoing
surgery, chemotherapy
and radiotherapy just
months before. The
Coast's Queen of Athletics
says exercise is "almost as
important as the chemo" in the
cancer equation.

Inspirational Margaret was a

I always exercised in the morning before I went to treatment as I often felt tired after...as much with the process of the treatment as the actual treatment itself. There were days when I felt my body was telling me to take the day off and rest, and I did.

Chemo is feared by many, but I knew that my body was strong and I could work through the side effects. I wanted to end my treatment as fit and well as possible.

My advice is to work at the lowest level on days you feel unwell or take the day off...but try to do something active on *as many* days as you can. Set a couple of goals and tackle them when you are feeling good! Having a trainer can help you get started, and it goes without saying always check with your doctor before exercising."



# Breastercise...

#### **Exercise & Breast Cancer**

#### with Dr Sharon Czerniec

Physiotherapist & Research Fellow- Australian Lymphodema Education, Research & Treatment Macquarie University



#### What are the specific benefits of exercise?

Research shows that regular exercise during and after breast cancer treatment improves physical and emotional wellbeing and quality of life.

Exercise can help with treatment and cancer related side effects such as fatigue, lymphoedema and decreased bone density. There is also evidence that exercise may reduce the risk of cancer recurrence and indeed if exercise was a pill it would be widely prescribed!

# I just had surgery...any advice before starting an exercise program?

- Be assessed for lymphoedema using bioimpedance spectroscopy if possible (see page 12). Early detection allows early treatment, which includes tailored exercise advice.
- Have your arm function assessed as breast cancer surgery can affect the co-ordination of the muscles around the shoulder. Arm dysfunction can be rehabilitated, but if not detected it can lead to pain as your exercise intensity increases.
- Get a professional bra fitting!

## What exercise programs are available on the Central Coast?

There are exercise programs that are specifically designed for women diagnosed with breast cancer (or with cancer in general).

 YWCA Encore is a free eight-week program of gentle floor and pool-based exercises for women diagnosed with breast cancer. Visit www.ywcaencore.org.au or phone 1800 305 150.

- Strength After Breast Cancer is a five session rehabilitative exercise program with focus on progressive stretching and strengthening.
   Visit www.lymphaticsolutions.com.au
- CoastCanCare Wellness Program runs free exercise classes for adults diagnosed with cancer. Visit www.cclhd.health.nsw.gov.au/ services/central-coast-cancer-services/ cancer-services/coastcancare/
- Dragons Abreast Australia is a national organisation of breast cancer survivors who get together to participate in dragon boating. theCoastBusters is the local group. Visit www. dragonsabreast.com.au or phone 0407 725 911.



#### **Top Resources**

#### **Exercise & Staying Fit by BCNA**

https://www.bcna.org.au/health-wellbeing/ physical-wellbeing/exercise-and-staying-fit/

Exercise During Cancer Treatment by Cancer Council https://www.cancercouncil.com.au/cancer-information/exercise-cancer/

# Fighting for the gurls

Her brother Alan developed prostate cancer

at 56 (related to the BRCA2 gene) and her nephew Morgan was diagnosed with Stage III

Her daughter Amy, 35, has tested positive

male breast cancer in 2018.

Janis Livingstone knows all too well the devastating impact of breast cancer...

It took her sister Sue at 58.

Her other sister Jenette had a preventative mastectomy after testing positive

for the BRCA2 gene and Janis herself was diagnosed in 2001.

And her eldest daughter Sarah, was diagnosed with Stage II breast cancer in 2015.

Turn the page to find out how this dynamic mother and daughter duo fought breast cancer head on.

# Janis Livingstone 67, EMPIRE BAY

"My first reaction after being diagnosed with breast cancer was one of pure, raw, abject fear 'Am I going to die?'

Thankfully I have a good friend who is an orthopaedic surgeon and he sat me down and took all the fear away by rationally discussing all the facts. I think expressing my fears verbally helped me to allay them.

When I was diagnosed, I decided to have bilateral mastectomy and later my ovaries removed. It was a challenging decision for me, but given my strong family history - the right one for me.

As a theatre nurse and surgical assistant, I was very lucky I had access to information through the medical network and that greatly influenced my decisions about reconstruction. Over the decades, breast cancer surgery has really changed. And I mean *really* changed. In the

old days, I remember asking male surgeons why women needed to have such big, disfiguring slashes across their chest. 'Because we have to get it all out,' they would reply firmly, with little thought of just how devastating a big scar could make a woman feel.

Now thankfully we have many more surgical options. I opted for a TRAM flap, which uses tissue taken from the tummy to rebuild the breast shape. The downside of this was feeling somewhat disassociated from my sexuality as I no longer



Janis' Motto

"The courage that matters in breast cancer is the kind that gets you from one minute to the next. This often means baby steps, one stroke at a time, one lap at a time – and always one day at a time."

had nipples. However, having my areola tattooed definitely made me feel more womanly again.

Now I regularly perform cosmetic tattooing for patients on the coast. A small thing, but in so many ways a big

thing, because it allows so many women to walk past a mirror and look and feel like a woman again. I guess this is my way of giving back."

# Sarah Livingstone 44, BALMAIN

"Back in 2015 whilst in the bath, my 10-year-old daughter looked up from the book she was reading and told me that my right nipple looked "a bit funny".

In retrospect, my right breast did feel a bit heavier than the left, but I had rationalised that many women had one boob bigger than the other.

Concerned, I went for a mammogram the next day and was delivered the devastating news that I had a 9 cm aggressive lobular cancer.

Oddly enough, I had tested negative for the BRCA2 gene, despite my family history. Maybe I was one of the unlucky one in eight women who just got breast cancer, or perhaps the gene pathway for my particular cancer hasn't vet been discovered.

In any case, it was an emotional rollercoaster, with the first two weeks being the worst. My bone scans showed there were "hot spots" in my sacrum and iliac bones which the doctor told me were quite possibly cancerous (but thankfully turned out not to be). I really thought that was the end and I remember just wanting to be around my kids and ringing Mum in tears. Mum sobbed with me and said she was afraid too, and that is what I needed as I had been putting on a brave face for everyone and needed to fall apart.

After my surgery I needed to go on an aromatase inhibitor to block any oestrogen

#### Sarah's Motto

"Don't let intimacy after breast cancer be the white elephant in the room. Feel comfortable with menopause changes – not shame and embarrassment. And don't suffer in silence"

which my cancer was very sensitive to. It meant

menopause hit me like a freight train – full blown hot flushes at 41.

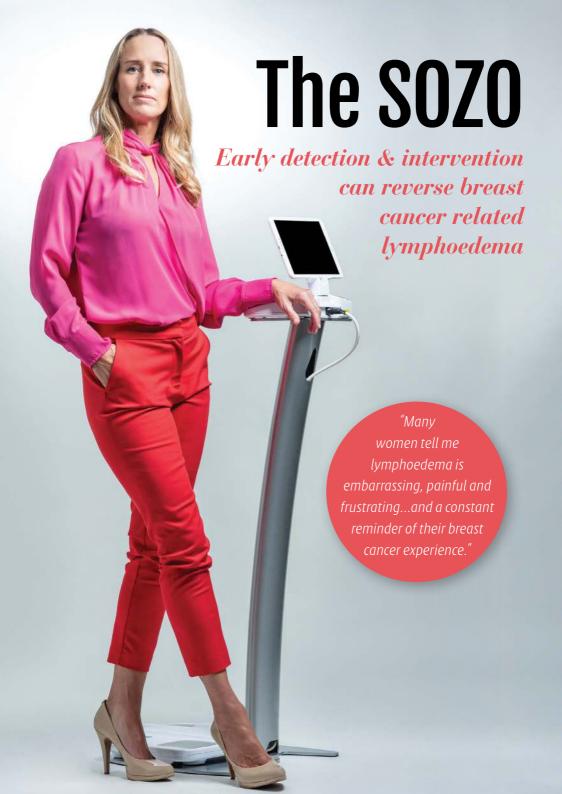
At one stage I was laughing, thinking to myself, I'm having so many hot flushes, the only part of my body that doesn't feel like it's on fire are my boobs (my implants felt like

two lumps of cold fish).

During this time, I also struggled with painful intercourse. But I never let on because I knew my wonderful husband would be devastated and not want to cause me any distress.

My specialist mentioned a trial involving Mona Lisa Touch laser treatment, which can help with the symptoms of dryness and painful intercourse after menopause. Lord knows if I was in the "control" group or getting the real deal, but I felt a dramatic improvement. More than that, I felt like a woman again at a time when having my breasts and ovaries removed made me feel completely androgynous.

For me, vaginal atrophy was another reminder of my cancer and cancer was something I couldn't change. Having treatment for it was was something I could do – and a year later I started my own clinic helping other women experiencing similar symptoms. Men have Viagra – that's a \$72 billion industry and now it's cheaper than a cup of coffee. Why shouldn't women feel sexy too?"



# **Early Detection of Lymphoedema**

#### with Kate Perkins

B App Sci (Occupational Therapist)
Lymphoedema Therapist & Cancer Rehabilitation Therapist

#### What are the symptoms of lymphoedema?

Lymphoedema can occur any time after breast cancer treatment which involves surgery and/or radiotherapy to the axilla.

Symptoms include aching, heaviness, swelling or tightness of clothes and jewelry. It can be a silent creeper without any early symptoms, or women may fail to act on minor swelling.

If left untreated, lymphoedema can become a lifelong chronic condition that can significantly impact a person's quality of life.

#### What's new in early detection?

Lymphoedema is not curable, but it can be reversible if detected early. The SOZO device allows detection of lymphoedema before symptoms are felt or seen. This latest technology is available on the Central Coast.

#### How does it work?

The SOZO device sends 256 painless electric currents through your body tissue to measure the level of fluid resistance. It has electrodes under the hand and foot plates which means testing is done standing up, clothes on and takes 30 seconds.

At the end of the test you will be given a L-Dex score. An increase of 6.5 units in L-Dex value from a healthy baseline indicates early lymphoedema, and this is when treatment begins.

#### How much does it cost?

The cost of initial and follow-up consultations is partially rebatable by Medicare (under the Chronic Disease Management plan - speak to your GP) and your private health insurance.

#### **Top Resources**

**Australasian Lymphology Association** www.lymphoedema.org.au/



# Joy Allsworth

"I was diagnosed after a routine mammogram with the mobile BreastScreen van at Bateau Bay.

When I received a letter to come back for more tests, I was not concerned as I had previously been called back but it was a false alarm. However, this time I was diagnosed with early cancer in both breasts.

Within the week, I had surgery to remove both cancers. I then had to undergo radiation treatment for six weeks and then it was taking medication for five years.

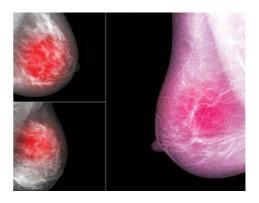
From the initial mammogram to diagnosis to surgery, it was only three weeks. It all seemed to happen very quickly. Suddenly, I had a lot of appointments to attend!

**The low point?** I guess it was a fall at home after surgery and tearing my rotator cuff, so having to get my arms above my head for the radiation treatment was quite painful. After about three weeks, I also developed radiation burns and my skin started to peel and the nurse had to apply paw paw cream and dressings to my breasts.

**The high point?** I was delighted when my radiation oncologist cancelled my last two treatments. It felt like all my Christmases had come at once!

#### 75, FORRESTERS BEACH

I must say though, aside from the side effects of radiotherapy, at no time did I even *think* I had cancer because the standard of care on the Coast was simply so good."



"Mammograms and imaging are your friends not your enemies. You can catch something early or rejoice if nothing is found. Either way you're ahead of the game."





## Suzanne Grahame 52, WYONGAH

"I had just turned 50 and during the year received three letters urging me to get a free mammogram. By the time the third one arrived, I started asking myself how many trees they were going to cut down because I hadn't done it.

So, I had my mammogram. A few days later, a letter arrived saying I needed

to have more tests. Then, it was a three day wait to find out what was going on. An hour before my appointment, my GP rang and told me to bring a support person.

My world turned upside down when I was told the devastating news that I had Stage III breast cancer.

There is still one thing that sticks out during the first 24 hours of being told I had advanced breast cancer. I was having a full-body scan when a staff member said: 'Well maybe we'll become best friends after this.'

I was devastated. I didn't want to be her best friend. I didn't want her to say that. If there is one message I would like to impart it is that people really need to be wary of the power of words.

They can be like poison arrows – even if people are well meaning.

After the scan I walked through the local shopping centre, completely numb.

A random lady flashed me a huge smile as she walked past me. A smile that I am alive and I

needed to fight. So I did.

I went through chemotherapy, surgery and radiotherapy. My scars were much smaller and more delicate than I ever imagined. I worked throughout my treatment, but cut down from 76 to 50 hours a week. My wonderful, supportive hubby Len and two

teenage sons Harrison and Zachary were my rock. And I also thank my medical team – everyone was

amazing.

wonderful hands "

To the women and men who had breast cancer before me, I say thank you, you have made my journey easier, and to those who are diagnosed after me, let me assure you on the Central Coast you are in

"From the start I decided not to read anything negative about my treatment and my motto was each day the sun rises, so will I and face things as they happen."

# Cancer Etiquette for Family & Friends

Good listening ears go a long way during treatment

When it comes to talking to loved ones about breast cancer, the power of words can never be underestimated – or the power of just listening overestimated. The women in this compendium have compiled a 'cancer etiquette guide' for family and friends based on their personal experiences.

#### **Treatment Etiquette**

Questions about treatment are often asked with good intentions, but can be intrusive.

Comments that make assumptions can also add stress when things may not be going so well.

#### **NEGATIVE OUESTIONS**

- ✗ "How is chemo going?" "Is it working?"
- "You look so well so things must be going OK."

#### **POSITIVE QUESTIONS**

- ✓ "How are you?" "How's things?"
- "Do you want to talk about the treatment?"

#### **Sharing Etiquette**

Some women are intensely private and want to disclose their own news, whereas others prefer friends to spread the news. Be respectful of individual wishes.

#### **NEGATIVE STATEMENT**

"Elsie has Stage III breast cancer, I just thought you should know."

#### **POSITIVE STATEMENT**

"Elsie, would you like me to tell anyone on your behalf? What would you like me to tell them?"



#### **Help Etiquette**

Small acts of kindness are usually appreciated, but large ones can be overwhelming.

Good ways to help include organising a Meal Train (<a href="www.mealtrain.com">www.mealtrain.com</a>), collecting kids from school and helping with housework.

"It is often difficult for women to ask for help," says breast cancer survivor Margaret Beardslee. "I remember once my brother-in-law and his friend popping over and my brother-in-law offering to wash his friend's car. Mine desperately needed a wash too but I was totally too proud to ask. So now I say, take up the offers ladies!"

#### Comparing Etiquette ...

No cancers are exactly alike, and no two patients respond to treatment the same way. However, all patients experience uncertainty.

While breast cancer survival outcomes are very good these days, not everyone is in the fortunate majority so hearing lots of stories about others' positive experiences can be overwhelming.

#### **NEGATIVE STATEMENT**

"My aunt had the same cancer. She's fine now and I'm sure you will be."

#### **POSTIVE STATEMENT**

"I have heard that everyone's breast cancer treatment is very different. I am thinking of you and wishing you the best."

Sometime silence isn't silent at all

# Secret symmetry



#### HEATHER'S STORY

"I had no idea I had DCIS (ductal carcinoma in situ). I spontaneously decided to have a mammogram when I saw the pink BreastScreen van in the supermarket car park.

Within 30 days from my initial call back, I had undergone bilateral mastectomy and reconstruction with implants. MRI had shown suspicious cells in my other breast so I wanted to remove all doubt and risk.

I did not need to have chemotherapy due to the non-invasive nature of the DCIS.

My diagnosis came out of the blue. No pain, no lumps. I had the all clear on a mammogram less than two years ago.

I later discovered this is fairly typical of DCIS, which rarely produces symptoms and is usually only picked up through screening.



I use rhubarb to colour my hair. I guess being a natural "hippie" helped me get through the experience too.

At diagnosis, I was told there were only two surgeons on the Central Coast and I had to choose one. I have since found out by talking to others there are many more options available.

I only had three weeks to decide about surgical options and found the online pictures of breast reconstructions terrifying.

I guess the reason I wanted to be part of this compendium is so people get a more realistic picture of the "real life" experience.

I dreaded telling my son Max, who has cerebral palsy and Aspergers, about my breast cancer diagnosis.

But he simply said in typical Max fashion: "Oh well you'll just have to get them lopped off Mum."

That pragmatism and sense of calm and normalcy really pulled me through when I needed it."

Heather wears Leila O'Toole swimwear

# **Bras & Prostheses**

### with Pauline Campbell

Professional Bra Fitter Leila O'Toole



Breast forms (or prostheses) have changed a lot since the days of solid silicone or foam. which were often hot and uncomfortable and sometimes mismatched to the original breast. Today, prostheses are feather light in comparison: about one third lighter than older style products. There is also a more extensive range of products available to suit all lifestyles. If you are into yoga or play sport, there are bras that give firm support and have an absorbent layer next to the skin. If you swim, you might choose a breast form that slips into a stylish swimsuit and allows water to flow through.



It's best to wait 6 to 8 weeks until all swelling has gone done so that your fitting is accurate.

#### Are there any specific products that can help women with lymphoedema?

The 'LYMPH O FIT' bra (\$199.95) with its burled surface has a massaging effect and actively promotes circulation of blood in the skin. It is front-fastening, breathable and super comfortable. It can be worn after all breast operations (including reduction and reconstruction) and should only be fitted by a trained specialist.



#### COSTS AND REBATE\$\$\$

- Silicone breast prosthesis range from \$330 to \$460.
- Partial breast prosthesis range from \$140 to \$170.
- Pocketed bras range from \$50 to \$125.

The Australian Government provides a reimbursement up to \$400 for each new or replacement breast prosthesis for women

who have had breast cancer surgery. You can claim every 2 years from your last purchase date. Also check with your private health insurance to see if you are entitled to a rebate.



## Denise Nicol 70, KILLGARE

There's no pay, no holidays, no superannuation or "time out" for carers. As Denise Nicol well knows, having a breast cancer diagnosis on top of being a carer is even trickier.

"After finding a lump in the shower, I was diagnosed with bilateral breast cancer on Christmas Eve in 2010.

Looking back, I accepted my diagnosis as a "natural progression", or others might call it an unlucky ticket in the genetic lottery. My maternal grandmother and sister both died from breast cancer - my sister passed away in 1991 two days before her 46th birthday.

Whilst some cancer patients have husbands and kids to care for throughout their treatment, I didn't. But I did have an ageing Dad and that was my main concern. At the time of my diagnosis, Dad was 91 and I was frequently travelling between his place on the Coast and my place in Lithgow. He was starting

to slow down as he was losing confidence in his cochlear implant. He also had heart and lung problems, so I was frequently driving to Dad's many medical appointments.

Nevertheless, many described him as a spritely nonagenarian and he really was because he came to all my appointments with me.

As the months went on, having a 91-year-old father who was declining in health was practically a full-time job of cooking, mowing lawns and running two households. And by the time I was fit for long-distance travel Dad wasn't, so I moved to the Coast permanently.

Since Dad's recent passing (he was 97), I went through his papers and unearthed his diary for 2011. He had noted on some occasions that I was "tired" after chemo. Though, I can only remember one occasion where I asked him to get a meal for himself.

During treatment, I didn't go into panic mode or anything like that. Maybe the prayers from the

ladies at church (some of whom are breast cancer survivors themselves) helped me stay calm. Life just carried on as before with a few more appointments – and this time they were mine."

My motto was to just accept what needs doing and do it.

# Mirror, Mirror on the Wall

Who's the best-dressed of us all?



From Snow White to Cinderella, if you can see the magic in the fairy tale it's a lot easier to face the future.

And that couldn't ring truer for women with breast cancer on the Central Coast who have reaped the benefits of more than \$100,000 raised by the annual Girls Just Wanna Have Fun fancy dress fundraiser at Ettalong Diggers over the past 10 years.

The theme for this year will be Once Upon A Time - so dress up as your favourite fairy tale character to celebrate the Coast's biggest Cancer fundraiser – with funds raised going towards cancer research as well as providing

Once Upon A Time

Oth Annual

Cancer Council Girls Night In

Saturday October 26, 2019

\*\*

ETTALONG DIGGERS | 6.30PM - 11.15PM

FANCY DRESS: FAIRY TALE AND STORY BOOK CHARACTERS

financial, legal and home help to local women with cancer.

From its fledgling beginnings in 2010, when a group of local mums started up a community fundraiser after two mums in their kids' kindergarten class were diagnosed with breast cancer, the night has grown to become the most popular cancer fundraiser on the Coast.

Gloria Gaynor, pink sequins and glitter balls were out in force last year when more than 370 Central Coast women converged on Ettalong Diggers to celebrate the sold-out Boogie Wonderland Disco in spectacular style. The night raised more than \$30,000 for all women's cancers and no doubt this year will be even bigger.

Just goes to show that one woman can make a difference - but together Coasties can rock the world!

Heartfelt thanks to local heroes Stacey, Margaret, Belinda, Sonja and Julie who have raised over \$100k for the Cancer Council on the Central Coast after starting the event up in 2010.



Many thanks to the inspirational women who have shared their breast cancer journey.



