

Endometriosis Association (Qld) Inc

CELEBRATING 20 YEARS

SUPPORTING SUFFERERS,
THEIR FAMILIES
AND FRIENDS....

On Friday 26th August 1988 an article in the Brisbane Courier Mail invited anyone interested in forming a support group in Brisbane for Endometriosis sufferers to a meeting to be held on 29th August 1988

This booklet commemorates 20 years since that first meeting.

1 9 8 8

20
Years

2 0 0 8



*I expect to pass through life
but once.*

*If therefore, there be any
kindness I can show,
Or any good thing that
I can do for any fellow being,
Let me do it now.... as I shall
not pass this way again.*

**William Penn
(1644 – 1718)**



While every care and attention has been maintained as we compiled this booklet we would like to apologise to anyone who we may have inadvertently overlooked or misquoted.

Elsbeth Jeffery & Jude Perryn OAM.
With assistance from Mr Chris Edds.

AWARDS

“..it is not one person; it is the coming together of a group of people all with the same aim in life – to make life a little easier, if they can, for their fellow sufferers.” Jude 2001.

Foundation members

20 years continuous membership

Beth Clarke
Mary MacPherson
Jude Perryn OAM

Life Time Members

Jude Perryn 2001
Beth Clarke 2008
Mary MacPherson 2008

Members 15 – 20 years

Ann Belby
Elspeth Jeffery
Gerry Murphy
Janet Tuckey

Members 10 – 15 years

Karen Hurst
Wendy Just
Alexandra Sparks
Tanya Swanton

Members in their 10th Year

Angie Pedron
Dr Gary Swift

The Association has been fortunate to receive assistance in many forms from many people over the years – personal time and expertise, money and other donations. We thank you all. Without you the Association could not continue to function.

The silent ones

We would be very remiss if we did not acknowledge the silent ones. Those members and friends who have been active behind the scenes on the Association's behalf.

THANK YOU

REGIONAL CONTACTS OVER THE YEARS

Sunshine Coast: Ann Sandringham, Anda Davis, Jaimey Bampton

Hervey Bay: Kerrie, Melissa Dyson (Hardham)

Townsville: Natalie, Brigitte Cook, Suzanne McHardy, Kath Wickham

Rockhampton: Jo Luck, Women's Health Centre

Toowoomba & Darling Downs: Julie Davis, Sue Ferricks, Tracey Cooper

Gold Coast: Di Abrahams, Melinda Clark, Penny Fenton, Nerina, Tracey Coghlan, Louise, Natalie, Irene

Bundaberg: Anna Marea Thompson

Cairns: Gail Harper

Barcaldine: Wendy Just

Stanthorpe: Judy Wills

Mackay: Kerry Gallard

Ipswich: Marina Brown

NSW: Brigid Thew

Partners and Friends

Support Workers through the Years

Ann Belby, Bronwyn Biddulph, Tracey Coghlan, Judi Cogliati, Anda Davies, Christine Davies, Kristine Davis, Daphne Davis, Julie Davis, Ann de Mattia (Black), Joanne Dickson, Katrina Dunks, Melissa Dyson (Hardham), Sue Ferricks, Julie Ann Finlay, Glenda, Melissa Gibson (Teenage support), Kim Goodwin, Wendy Green, Corinne Hobin (Harrison), Jo Hope, Wendy Hughes, Elspeth Jeffery, Heather Koelmeyer (Roberton), Janet Lange, Michelle Lindley, Stephanie Maddison, Trish McKenna, Kylie McCluskey, Megan McCormick, Mary MacPherson, Gerry Murphy, Jeanette Nobes, Karen O'Hara, Jude Perryn, K Reilly, Dianne Rippon, Darlene Scott, Jo Ann Tyson Carmel Wallace, Ann Weeks, Jennie Wilson, Cathy Wright, and Lyn Zipf.

There have been a few times when due to lack of volunteers we thought that the Group could not go on. The Association will always be grateful to the members who over the years stepped forward to give 101% of themselves. In particular we would like to thank Trish McKenna for taking on the 2 busiest committee positions and agreeing to be both President AND Secretary in the one year.

PUBLIC NOTICE

The Rights and Responsibilities of Support Visitors 1989.

RIGHTS:

- The right to training – effectively planned and presented
- The right to ongoing education and skill development
- The right to be considered as a skilled worker whose opinion and suggestions are valued
- The right to support and guidance from the Co-ordinator at all times.
- The right to a suitable referral which takes into consideration personal preference and life experiences
- The right to "Time Out", or to refuse any request for a patient visit.
- The right to terminate commitment at any time

Qendo's original rules

RESPONSIBILITIES:

- To maintain responsible attitudes and ethical standards in volunteer work
- To be willing to undertake training and to attend, as far as possible, ongoing training sessions
- To be reasonably available to make support visits as requested, and to notify the Co-ordinator of any absences
- To accept a referral with commitment – i.e.
 - a. Make contact promptly
 - b. Record details of visit
 - c. Direct any special concerns to the Co-ordinator
- Maintain strict confidentiality of client information
- To provide information in a responsible manner and offer no advice on specific medical matters, Doctors or Treatment

ROLE OF THE CO-ORDINATOR

- To arrange for, or provide, well organised and effectively presented training for Support Visitors
- Accept referrals for visits and select a suitable support visitor
- Provide ongoing and accessible support and guidance for Support Visitors
- Maintain confidential records of Support Visitor and Client details, referrals and visits
- Report to Volunteer Programme Sub-committee as required
- Arrange for accurate evaluation of Support Visitor Programme and provide reports as requested by the Association.





“How fortunate are those who share the blessing of friendship
It involves many things, but above all,
The warmth of understanding, the comfort of companionship,
And the joy of appreciation.”Anon



Happy Memories - The excitement when one of our members falls pregnant.

Member's Reminiscences

I remember trying to get information about endometriosis following my diagnosis, and more importantly how to live with endo, and I seemed to run into brick walls in every direction. In the 1980s in Australia, there was little knowledge of this disease in the general population, let alone the medical profession, and a lack of information available. It was only after contacting a relative in Canada that I learned about the Endometriosis Association in the United States and wrote to them asking for information. Several weeks later I received a large envelope stuffed full of leaflets and information. I ran upstairs with the envelope and everything else stopped while I sat down and devoured the contents of that envelope. I still remember the feeling of finally finding out about other people's experiences for the first time.

Following this, I wanted to make contact with others who also had endo to share information, experiences and advice. My initial attempts to find others by word of mouth were fruitless. Finally, I made contact with the Lilian Cooper Centre and spoke to Dr. Sheila O'Neill, the founder of the Lilian Cooper Centre, about my plan to form a support group. Connecting with others and finding a place to meet were the two main hurdles. Sheila immediately offered the use of the Lilian Cooper centre for our first meeting. With this issue solved, I was able to place a small article in the Courier Mail and received a number of phone calls in response.

On the day of the very first meeting I worried if anyone would come to the meeting. I thought if a few people turned up it would be a good result. People started to arrive shortly before the meeting time and the Lilian Cooper Centre filled up and then people began overflowing outside. It quickly became obvious the centre would not hold everyone. Sheila O'Neill phoned St Andrews Hospital and organised a meeting room to accommodate us there. People kept pouring in and then that room soon filled up. There was standing room only in a room designed to hold about 80 people, which held close to 100 people. And everywhere women were, often for the first time, meeting with and talking to other women with endo.

That meeting was a healing time for many people and the start of something that has become bigger than all of us.

Ann Black (De Mattia)
Foundation President



Member's Reminiscences

I was finally diagnosed with Endometriosis at age 19 in 1978. At the time I felt isolated as I had never heard the word before and knew no one else with this debilitating disease. My husband (Allan) was reading the Courier Mail and saw an advertisement seeking other Endo sufferers with the idea of forming a support group for sufferers and their families. I rang Ann and as they say, the rest is history!. I was the only one of many people there who had a pen and paper to take notes. It was decided to form a steering committee, and as I had the pen and paper, I was elected Secretary. This position I held for 2 years, I stepped down to fulfil family commitments. I continued to be a member of the Steering Committee until a transfer to Rockhampton (Allan worked for QRail) in 1994. I remember setting my "office" up in the stairwell of our house (boy, did it get a bit warm in summer under there!) It was tiny but FULL of boxes of pamphlets, a desk with typewriter, membership cards (all our members were on cards then and most everything was hand written!) You can imagine the work we had to do. All our newsletters were processed on a manual typewriter and proofread about 3 times before being photocopied. But, alas, some mistakes did get through! Computers were still fairly new and VERY expensive. Oh, but so many happy memories.

I am a firm believer in the Association and can't thank them enough for the support given to me and my family and the lifelong friendships I have made.

So, A BIG THANK YOU to the Association and its members and keep up the excellent work. I know you will be around for AT LEAST the next 20 years.

It has been a privilege having you in my life - keep smiling.

Beth Clarke
Foundation Secretary



Member's Reminiscences

While Brisbane's biggest party was happening with EXPO, the Endometriosis Association (Qld) Inc was born. In 1988, having read Ann DeMatia's bravely conducted interview about Endometriosis published in the Courier Mail, I felt encouraged to join others in the hope of better understanding this condition. We knew from the overwhelming number who attended that meeting that we had to support each other and form the much needed association.

It is so easy for me to consider how my involvement with the Association helped me over the years; especially the first ten years of my twenty-year membership. Firstly the friendship & support given to me by the girls, their partners, families and friends included, the learnings from our medical contacts (allied health as well as expert medical specialists), the business acumen in running an association and the fun times we had in fund-raising activities. Though each of us suffered in such varied ways with Endometriosis and its complications, (from infertility to the monthly nightmares, the surgery and drugs), we stayed positive through genuine concern and helpful tactics being shared.

Volunteers can offer so much to others and gain so much themselves. Career-wise, I gained the confidence as a public speaker, organiser, medical specialist liaison and even exposed a creative side through fund-raising which led to studying marketing. Personally my gain was greater! Learning to take action to empower one's self to take control was encouraged; hence the positivity.

I keenly maintained my membership to stay updated via the newsletters which I look forward to reading and am happy to refer others in need of assistance. I wish the Association well, all its members and those it supports.

Mary MacPherson
Founding Member and Former Vice President



Member's Reminiscences

Years of misdiagnosis and anguish came to an end in 1979 when, after a hysterectomy, I was told that the cause of my troubles was Endometriosis. When I read the Courier mail article in 1988 I knew I wanted to be part of this support group. There was so little information available about Endometriosis back then. In the early years the support workers were constantly on the phone to Dr Kevin Forbes or Dr Sheila O'Neill asking for information to help our callers. I believe that The Association has played a large part in changing the community's perception of this complex condition.

The highlight for me was in 1988 hearing Dr Kevin Forbes say that Endometriosis could reoccur after a hysterectomy – oh bliss – I knew how to treat that. My symptoms had returned and up till then the thought that I might have something much worse was on my mind. I must admit receiving the OAM comes a close second. The low point was receiving the telephone call telling me that Kim had passed away.

One year I made a passing remark that I had held every position on the committee except Secretary. Needless to say that was the position I had the following year.

Some of my memories are of:

Being on the sub-committees

- Writing the Constitution
- Obtaining Gift Fund status
- Writing the original Endometriosis and You brochure
- Formulating the original strategic plan (was that really 16 years ago!!)
- Sending out 2000 invitations to the 10th anniversary seminar to Drs in 1998 and having to keep them in post code order. Then having to cancel the event as only 10 Drs responded.

The many fundraising auctions and events, the social get togethers, the many picnics/BBQs in the parks of Brisbane, The joy of watching the next generation come into this world. often to members who had been told it was an impossibility, Meeting the members from the international support groups at the World Congress in March

For 20 years I have had the pleasure of watching the Association grow. There have been so many amazing people pass through the Association. I have made such wonderful endo friends over the years. We have shared the highs and lows over many cups of coffee or that occasional glass of wine (or should that be many glasses of wine?). Thank you all for the memories.

Jude Perryn

Foundation Vice president and life time member, Vice President 2008



Member's Reminiscences

My journey with Endo commenced with years of pain throughout my teenage years and being treated as if I over reacted to period pain. Every month, Mum was called to get me from school and put me in bed with pain killers. Then when diagnosed at 26 I was told to get pregnant to fix it. When I said that didn't suit me, the doctor said "Oh, you're one of them women.... a Career women....". Suffice to say, I changed doctors and went on the great ride of hormone therapy, drugs and 8 surgeries all up (to date!).

One of my memories of QENDO would be the fabulous chat from Megan the first time I called the support line and then getting a parcel of information in the mail from her. She was just so understanding and caring. I hope I have had that impact on some of the women I have talked to on the support line too. And the great laughs and good times I have had with all the members be it at a Trivia Night when we are making everyone put their hands into jelly to retrieve tickets for the raffle, or the many hours whittled away at Coffee Clubs across Brisbane.

Michelle Lindley
Former Vice president

Member's Reminiscences

Nobody told me that endometriosis can run in families. We found out the hard way. My endometriosis was diagnosed finally in 1990 after many years of pain and being told it was normal. A friend told me about the Endometriosis Association and I joined, not knowing what to expect. I found hard (up-to-date) information and the comfort of other women's stories—I was not alone and felt more in control of my condition. Circumstances then led me to drop out in 1995.

Then unbelievably ten years down the track my teenage daughter was diagnosed with the dreaded endometriosis also. We had no hesitation in joining and me rejoining the Association. We don't know what is ahead for Natalie but to know that there is a support group and information on hand is wonderful. We all need help along the journey of leading a normal life and not letting endometriosis rule.

Elizabeth & Natalie (Mother & Daughter)
Secretary 2008



Member's Reminiscences

On reflection of the most significant memories I have of the Endometriosis Association, the one thing which stands out is the caring and supportive nature of the people who are involved and as a result the lifelong friendships I have developed.

Information is the key for sufferers of Endometriosis, so the newsletters and speakers at our meetings and seminars have been most important in helping me deal with the disease myself and subsequently assisting me to help others. Not only the knowledge imparted, but maybe the humour with which it was delivered (we all need good a laugh). One speaker would march all over the dais whilst speaking and the committee members would have to think of many & varied ways to cater for that speaker so we could all hear what he was saying!, another waved the "laser light thing" all around the room. Foremost has been the generosity and supportiveness of those who helped in so many ways. Other meeting memories include the wide range of subjects covered and the meeting places we have used for free or otherwise. As well, the cockroaches that joined us at our yoga classes! and who will forget the partners meeting when the men spoke of their experiences and had us all in tears.

Committee meetings have provided all manner of pleasure – the talking, laughing, crying, eating and dare I say it, swearing at the technology, particularly at newsletter time. Social occasions and fund raising have provided the opportunity for us all to get to know each other even better. One of our memorable social occasions was at a restaurant whereby we socialized with a group of gentlemen at a bucks party, on a table near us. By the end of the night they were taking home, and handing out brochures to everybody at the restaurant and any passers by, much to our amusement and appreciation. One waitress told us she had endo and said that she would join the association.

Fundraising is of course paramount for any voluntary organization but once again the hard work and commitment put in by the committee, family and friends make it all worthwhile whether it be the gala dinners, raffles, bulbs, putting together cookbooks, making cards and craft, or winning or losing at trivia nights.

To my mind the generosity of all kinds has been the most significant aspect of the Endometriosis family.

Elsbeth Jeffery



Member's Reminiscences

It has been more than a privilege to have been a friend of the Endometriosis Association (Qld) Inc and its patron since 2006. I feel that researchers have a responsibility to communicate about their research to those suffering from the medical conditions they are studying. I have tried to give a little back, but I really think the scales are weighted more in favour of the benefit given to our research by members of the Association.

My memories of the Association go back to 1993, when I had been trying to obtain national funding for a study of gynaecological reasons for why women were having hysterectomies. Dr. Dan O'Connor had asked me why we weren't investigating endometriosis and between us we found funding for a twin study that was run from Queensland Institute of Medical Research (QIMR) in 1993-1994. Yes, it looked like endo was running in families. In 1996 I moved back to work at QIMR and we found funding to start recruiting women in families where sisters had been diagnosed. Dan O'Connor suggested that I contact the Association. I did. It was the beginning of a great relationship.

I remember Anne Belby, who was warm and dynamic and the President at that time, and fantastic women like Gerry Murphy. A significant memory is speaking at the 10 year reunion at the Professional Development Centre at Bardon on a wet evening. How can that be 10 years ago? I recall thinking what fantastic women would spend so much of their time trying to help others with endo. I remember the inclusiveness of the meetings and the number of young women who came with their partners. I think of the mothers who came because their daughters had endo, and some of the mothers had had it as well. Not only were the mothers there in force (e.g. Elspeth Jeffery and Jude Perryn), but there were the husbands and fathers as well (e.g. John and John)! So many members of the Association have helped our research, often along with their parents and siblings and partners. The support of the Association has been very important and the contact with members keeps us grounded in why we are doing the research.

Then came Kim Goodwin. Kim's story about her diagnosis was very moving, as was Jo Hope's and Bronwyn Biddulph. So many young women had had a hysterectomy. I admired these brave women and the desperation they must have felt. Kim in particular was determined to help our research and to build the relationship with QIMR. She helped raise money for our research and QIMR was happy to run tours for members and have Association AGMs at the Institute. Kim was a dynamo despite suffering severely from complications of endo and so tenacious in pursuing ends to further the message about endometriosis. I was touched that Kim would invite me to Association social functions at her home, and through this I met her supportive parents Allan and Jill and her sister Susan. When Kim's life ended so tragically at such a young age, I was again privileged by being included in the group that met at Jude and John's home to share our feelings of shock and loss and grieve together.

One stand-out memory has to be the glamorous gala fund-raising auction and entertainment event that Kim and other members organized at the Stamford Plaza hotel in Brisbane. It was quite a night, attended by many with a personal and professional interest in endometriosis! The then patron, Paula Duncan, was memorably glamorous, as were members of the Association. I recall sitting at the table with current President Judi Cogliati (gorgeous in red) and husband Mareno.

Member's Reminiscences

There are so many memorable women and family members whose warmth and openness I value. It has been a privilege to have been involved with the Association. I wish members all the best personally and congratulate the Association on all achievements over the past 20 years. To be the last remaining Endometriosis Association in Australia shows extraordinary determination and commitment. Members who have been 'in there' for endo for the Association's 20 years are truly inspiring.

Dr Susan Treloar 2008



Member's Reminiscences

In a sense, I feel like I grew up with Endo. Mum had it when we were kids and I remember doing research on Endo for an assignment in high school. Then Mum found the Endo Association and it was a saviour for her. My memories of that time include dropping Mum off to newsletter folding "parties". It seemed like they were getting together for fun. Everyone had plates of food and there were lots of laughter and smiles...I had no idea they were doing work as everyone looked so happy. I have memories of Mum's Endo friends visiting the house and these people remain lifelong family friends to this day.

After many years of avoidance and weird misdiagnoses, I finally had to accept that all my symptoms were likely to be Endo and finally took the plunge to have a laparoscopy just weeks before getting married and moving overseas. A turning point in my life was the seminar for partners that we attended as newlyweds and although overwhelming in some respects, the support it provided my husband and I through the Endo journey was invaluable. I have been involved with the association for eight years, and have volunteered for five of those. It gives me a great sense of belonging and self worth to be involved with the association and I appreciate all of those who have supported me, especially those who are being honoured for their extensive involvement over the past twenty years. Congratulations to Qendo on reaching 20 years, and best wishes for the next twenty!

Katrina Dunks
Treasurer 2008 and Support Worker



Member's Reminiscences

Challenges that I've faced with endo, well there's been a few over the 11 years since my diagnosis. One major one was prior to my diagnosis and trying to get through to my GP that there was something wrong and it wasn't "period pain" as my diagnosis took over 4 years to happen.

Another challenge was to my fertility. Being told at 20 (a full time uni student living at home and with no partner) by the same GP to "go and get pregnant, it will solve all your problems". Also the unknown with my fertility, will I have problems conceiving? Would I conceive at all? Will I find a partner who'll put up with all of this?

I also found talking to people about the disease, or well not talking to people as I got sick of trying to explain to people what endo was and what it meant to me and also to get over the embarrassment barriers people put up when talking about a "women's condition" was very difficult and trying. I'm sure a lot of people thought, "Well you look OK" or you don't look like you're in pain so what's the problem?!

Also, financial outlays for constant surgeries, medications, procedures, vitamins, supplements, acupuncture, health insurance.....

Then the personal costs, on relationships and family. The yo-yo of emotions while on hormone treatment etc. etc. etc.

But when I look at the bigger picture, I was handed these challenges for a reason. I have had the strength and support to have overcome the most major challenge of falling pregnant and having a healthy baby and still maintained some degree of sanity!!!

Mia Bowen
Secretary 2007



Member's Reminiscences

A for affirmation
S for support
S for sounding board
O for others
C for comforting
I for inspirational
A for amazing
T for tireless
I for interested
O for optimistic
N for nurturing

These are the words that first come to mind when I reflect on what the Endometriosis Association has offered me and countless women and their families over the years.

I remember when diagnosed in 1995, the fear and anguish that I felt about having this “unknown” disease. But even more so, I remember with gratitude, the warmth and compassion I found at the other end of the phone when I first spoke to a support worker, Elspeth. It enabled me to go from feeling overwhelmed and unsure to becoming encouraged and empowered to face my future with hope not despair, strength not fear.

I believe that same gratitude I felt is why many of us decided to “give something back” to a support group that gave something unique and priceless to us – human kindness and understanding when one needs it the most.

A re-assuring hand out-stretched to another, a kind-hearted and non-judgemental ear, the imparting of valuable and vital information, a constant beacon of light through the darkest days with endo, are what has helped make the Qld Endo Association what it has been to those who needed its wisdom, compassion and empathy.

Through the many meetings sitting in a pew at the church at Auchenflower, countless hours and days creating and folding the newsletters, attending clinics & coffee get-togethers, participating in Support Worker training workshops and educational seminars, many treasured friendships were formed while building and nurturing an Association that strived to make a positive difference in the lives of women as they travelled along their journey with Endo.

“Only when one has walked in another’s shoes, can they ever truly understand”. The Endo Association has not only walked in another’s shoes so many times over the past 20 years, it has unselfishly and gently left unforgettable footprints in the hearts, minds and lives of many women and their family and friends living with endo and those of us who were privileged and humbled enough to share in their journey.

Bronwyn Biddulph
Past president



Member's Reminiscences

Like all women who have contacted the Association over the years, I had been clinging to a hope, the chance of a lifeline, to know that you weren't so alone with this word, this condition that you had never heard of before! I received that lifeline and was very relieved to find myself surrounded by women who not only knew what I was dealing with and going through, but who actually understood what having endo meant. It put life in perspective as there were so many women and their families worse off than me and mine! The lifelong friends I have made and the real life stories that have inspired me over the years I know have made me a better person. I would not trade my years volunteering for the Association for anything and am grateful for the opportunity to have been involved with such a wonderful, dedicated group of women. I would also like to make special mention of Kim Goodwin, a warm, compassionate, gentle person who was taken from us before her time, you are missed dearly my friend everyday!

There are a few incidences that still make me laugh.

Macupants (underpants with magnets - for Endo pain) definitely springs to mind as one of them! How much mileage (and laughs) did we get out of those!!

Probably the biggest one for me though was when my friend Kim Kempthorne spoke at one of our meetings at Wickham Terrace and was mugged getting into her car in the carpark just around the corner and her handbag was stolen. She was taken to the hospital to get checked out and Gary Scarlett looked around for the perpetrators with no luck. Kim, thought it was her duty to warn people in the area, she leapt in front of this German tourist, who spoke very little English, and tried to warn him of the danger in the area. The tourist, judging by the "deer-caught-in-the-headlights" look on his face obviously thought Kim was the danger and nearly had a heart attack (he was only a young man by the way!). He spoke to the Police who were there at the time and they managed to convince him somehow that she wasn't a threat! It was one of the funniest things I've seen and I constantly liked to remind Kim of it, even when in hospital and I would visit her. I was then accused of trying to burst her stitches from making her laugh!

I joined the Association in June 1999 and was on the Pager roster pretty well straightaway. I think I was Secretary for four years from 2001-2005 and Pager Coordinator for 2004-2005. My love to all

Darlene Scott
Past Secretary



Member's Reminiscences

AFTER 10 years of suffering from what I was constantly told was just very bad “period pain” I was finally diagnosed with Endometriosis at 23.

From my early teens I realised the pain that I experienced couldn't be normal but it was always put down to period pain. As the years went on the pain became more frequent, had me bedridden more often and was interfering with my quality of life as I was often exhausted and too sore to do anything. With the pain came nausea and feelings of faintness and my weakened immune system ensured I caught every lurgy that came along.

When I was finally referred to gynaecologist Dr Julie Lindstrom in 2001 with the prospect of having endometriosis, she suggested a laparoscopy ASAP. However, when I was at last diagnosed with endo it was a bittersweet moment as I finally had a reason for why I had been in so much pain over the years, but with that came the possibility of many more years of pain and the realisation that I may not be able to have children.

Since then I have had a second laparoscopy and am due for my third later this year. The older I get the worse the endo seems to become and there are days when I struggle to get out of bed in the mornings to go to work.

When I joined the Endometriosis Association (Queensland) in 2001 it was a godsend to be able to end the isolation I had previously felt as an undiagnosed endo sufferer who didn't know any other endo women.

I looked forward to every newsletter but each one proved emotional as I would often cry and sympathise with the brave women who bared their souls in the touching “I” stories.

The association has been a lifeblood of support to myself and many other endometriosis sufferers and I am sure that it will continue to thrive for another 20 years; for its positive contribution to women with endometriosis is incomparable.

Stephanie Maddison



Member's Reminiscences

I congratulate all members of the Endometriosis Association (Qld) Inc on their 20th Anniversary. It has I am sure, been a very rewarding journey to know you have provided much needed assistance and support for women consistently over the years.

A support group needs dedicated members to maintain the service and we all need to acknowledge the sterling efforts of the many people who have kept the Association going so strongly and for so long. You are also recognising three members who have maintained 20 years continuous membership. This honour is richly deserved.

It was my great privilege to work with your Association in the first years and the inevitable ups and downs as you sorted the relationship with other Associations and support groups. I also assisted with the production of the first brochure. They were exciting times and I will always fondly remember working with the team to build an effective support group. I still receive the newsletters and am constantly reminded of the good work you all have done over the last 20 years.

Once again congratulations to you all for the continued success of the Endometriosis Association (Qld) and I am sure that you will have continued success over the years to come.

Associate Professor Kevin Forbes
Head Years 3 & 4 MBBS Program
The University of Queensland
Foundation Medical Advisor



Through the Years

1988

The Inaugural Committee members were:

President:	Ann de Mattia
Vice president:	Jude Perryn
Secretary:	Beth Clarke
Treasurer:	Lynda Sauer
Minutes Secretary:	Sue Ferricks
Publicity Officer:	Jude Perryn
Medical Representative:	Dr Kevin Forbes
Education Officer:	Mary MacPherson
Resources Officer:	Julie Cleeton
Floater:	Sue Ferricks
Teenager Support:	Toni Bryden & Sue Ferricks
HRT:	Lyn Zipt & Cathy Barrett
Older Ladies:	Bernadette Ryan
Country Floater:	Sue Olsen
Impaired Infertility:	Mary MacPherson
Singles:	Lynda Sauer & Julie Cleeton

Initial goals:

Support

We are a group of people with a “sense of purpose”

We are a support group for endometriosis sufferers and their families.

We will provide crisis call help and hospital visitation from appropriate people to those who need these services.

Education

We will have access to and provide other members of the community with Accurate, Informative Literature

Newsletters with group news

Provide Educational speakers for ourselves and other interested people in the community.

Research

We aim to contribute to continuous data gathering and to raise more interest in the community and more funding for ongoing research into this disease.

Committee and General Meeting rooms used during that year were many and varied. Seven meetings were held and we only used the same premises once.

1. St Andrews Hospital - Seminar room
2. Lutwyche senior citizens,
3. St Andrews Hospital - Seminar room
4. Lillian Cooper Centre
5. Scout Hut Dutton Park
6. Millipond St Banyo S/C
7. Bardon Professional Development Centre

- The 2nd general meeting was held at Lutwyche Senior Citizens Hall, 140 people attended. The Association did not have a bank account or funds at this stage and we were hopeful that we would receive enough donations at the door to cover the cost of renting the hall. Ann de Mattia and Jude Perryn watched with interest as the donations were counted at the end of the night as they had gone surety for payment of the rental. Happily the cost was covered and a very surprised caretaker was paid the rental in coins and a few notes.
- Dr Kevin Forbes was the guest speaker, followed by a question and answer session. One item to come from that talk was that endometriosis could reoccur after a hysterectomy. It is interesting to note that there has not been a lot of change in attitude since 1988. The most telling answer then as now is that **“prevention will come when we know what causes it”**
- A tape was made of the talk and made available for borrowing by country women.
- In the early days a donation box was placed at the front door.
- Original membership was \$5.00 pa but on 28/11/88 it was increased to \$10.00
- The first grant received from the Brisbane City Council was for \$250.00 on 28/11/88
- A topic for discussion in 1988 was “50% of women overseas don’t take HRT after hysterectomy. A comment was made that it would be interesting to see what the consequences will be re osteoporosis in 20-30 yrs”. We are now 20 years on and must wonder if anyone ever followed up on these statistics.
- Financial membership base of 53 people

1989

Committee:

President:	Ann de Mattia
Vice president	Jude Perryn
Secretary	Beth Clarke
Treasurer	Linda Sauer
Minutes Secretary	Sue Ferricks
Publicity Officer	Julie Cleeton
Newsletter Editor:	Beth Clarke

- The Bardon professional Development Centre became our “Home Base”
- April – application for a grant of \$7500.00 from National Agenda of Women’s grants programme for the production and distribution of brochures. Aims:- actively creating community awareness of the disease and its consequences by production of educational literature, and through media outlets. 1:3 women suffer from endometriosis. Literature to be sent to outback medical centres, Flying Doctor , Women’s Groups to reach as many women as possible in Australia.
- The Constitution was written and submitted to the Justice Department for approval.
- DEVITT approved a grant of \$1000.00 for the training of crisis care counsellors which the association renamed support workers
- Over July & August the first support worker training programme was conducted at the Bardon Pre School. It comprised 6 sessions of 2 hrs over 6 weeks run by Kerry Batchler BA Dip Couns. Members to complete the first training course were Sue Ferricks, Heather Koelmeyer (Roberton), Trish McKenna, Mary MacPherson, Jude Perryn, Carmel Wallace, Jennie Wilson and Lyn Zipf.

- August – printing of ‘Endometriosis and You’ 20,000 copies at a cost of \$2192.00, 10,000 letterheads, 5,000 business cards and \$5,000 with compliments cards, at a cost of \$726.00. Books were purchased for the library with the remainder of the grant money
- December - request for grant \$15,000 from National Agenda of Women’s grants programme for - Aims: for the maintenance of an effective organizational operation and necessary educational, support and research activities. Plus the establishment of a central information point for personal contact with immediate feedback.

1990

Committee:

President:	Ann de Mattia
Vice president	Mary MacPherson
Secretary	Beth Clarke
Treasurer	Jude Perryn
Publicity Officer	Trish McKenna
Educational Officer	Julie Cleeton
Newsletter Editor:	Sue Ferricks

- Ann de Mattia spoke at the IVF group “JABS”
- 1,000 Information kits printed from funds from National Agenda for Women’s grants Programme.
- Tapes of the presentation by guest speakers at general meetings were produced and added to the library for borrowing by members. They included:
 - D Mcleod - Naturopathy and Endo,
 - K Anthony – Nutrition,
 - K Forbes - Advances in Endo Research Aug 89,
 - Dr M Williamson - HRT
 - Sterling Auditorium Gynaecology Service – Endometriosis.
- Sterling Pharmaceuticals Qld donated 6 books for the library “Endometriosis – an Enigma” as well as a donation to meet the costs associated with printing and postage for the initial seminar held at Bardon Professional Centre.
- “Coping with Endometriosis” by added to library
- An engraved pen presented to Dr. Kevin Forbes when he spoke on endometriosis research at the 2nd anniversary
- Mr Sid Everingham counselling psychologist for Catholic Ed spoke on Grief and Loss.
- ‘In Brisbane Today’ morning TV programme featured a segment on Endometriosis – there was an overwhelming response.
- The 1st Seminar for GP’s was very successful. -39 GP’s, 2 registered nurses as well as association members attended. There were 7 guest speakers – 4 specialist obstetricians, 2 GP’s, and 1 Psychiatrists. It was held a Bardon Professional Development Centre.
- The Association was asked to participate in interviews with 2nd year medical students. As part of their course they had to report on the effect of a chronic illness.
- There were 140 members

1991

Committee:

President:	Jude Perryn
Vice president	Ann De Mattia
Secretary	Trish Mc Kenna
Treasurer	Harriet Perryn
Minutes Secretary	Heather Koelmeyer
Committee Members:	Mary MacPherson Tanya Schramm Lyn Zipf
Newsletter Editor:	Sue Ferricks

- Rooms at “Alexandra” 201 Wickham Terrace were sourced and the contract was signed. It was good to finally have our own home for committee meetings, telephone enquiries, information giving contact for carers, support visitors, library and tape listening facilities. The rooms were manned by Harriet Perryn and were open Weds & Fri 10.00am -3.00 pm. Mondays were added later 5.00 – 6.00pm. The rooms were open by arrangement, out of hours, for personal appointments with a Support Worker.
- Guest Speakers at general meetings during the year were Dr Jane Howard – specialist in sexuality and Dr Kevin Forbes on the complexities of Endo,
- Mr Sid Everingham gave a workshop on “Coping in the ‘90’s” 15 persons, including 3men and 3 children attended.
- 16th November – fund raising \$100.00 commission from a garden tea party at Bardon Pre School (\$7.50 entry fee)
- **Thank you** for support to:- Sterling Winthrop, CSR, Narelle Sibley, Wendy Edmond, MLA, Health Department, Peter Carne Solicitor, Mary Ryan Book Shop

1992

Committee:

President:	Tanya Schramm
Vice president	Mary MacPherson
Secretary	Trish McKenna
Treasurer	Heather Robertson
Newsletter Editor:	Sue Ferricks
General Committee Members:	Linda Hollis, Cathy Keighly, Cheryl Osbourne, Denise Thomason, Maree Scurr

- Dr Kevin Forbes spoke at the 4th Anniversary meeting. Giving an update on endometriosis including its cause, pain treatment, surgery and IVF
- Fund raising: - lingerie party, and a movie Night – “**1492**” social and financial success held at the Village Twin.
- In August donations from Johnson & Johnson Pacific and City of Brisbane Benefit Fund allowed for the 1st strategic planning meeting which was held to rewrite the Mission Statement & Goals – included funding, communication, administration, promotion.

- The 2nd Support Workers Training Programme was held – 2nd – 4th Oct from Fri 6.00-9.00pm Sat 9.00 – 1.00, Sunday 9.00 – 1.00pm at the Endo rooms on Wickham Terrace
- Regional Support groups established – Gold Coast, MacKay, Toowoomba and the Sunshine Coast
- ‘I’ stories commenced in the newsletter
- The Pager service was introduced

1993

Committee:

President:	Tanya Schramm
Vice president	Mary MacPherson
Secretary	Trish McKenna
Treasurer	Heather Robertson
Newsletter Editor:	Sue Ferricks/

General Committee Members: Linda Hollis (until March), Cathy Keighly, (until March) Cherly Osbourne (transferred) Denise Thomason, Maree Scurr, Jude Perryn

- Most Committee meetings were held by telephone conference.
- Planning commenced to hold seminar in MacKay. The sub committee which comprised of Jude Perryn , Mary MacPherson, Dr Kevin Forbes and Tanya Schramm held four planning meetings. For varied reasons it was decided that the event would not go ahead
- Guest speakers at meetings were Julie Taylor on Nutrition and Helen Hartley, Physiotherapist on pain management.

1994

Committee:

President:	Trish McKenna
Vice president	Maree Scurr
Secretary	Trish McKenna
Treasurer	Denise Thomason
Minutes Secretary	Heather Robertson

General Committee Members: Ann Belby, Genny Edmonds, Wendy Hughes, Dianne Rippon

- General Meetings guest speakers included:- Dr Cherrell Hirst – Breast Cancer Dr K Forbes new drugs Zoladex & Synarel, Michael O’Keefe – Exercise Physiologist & director of Wesley Corporate Health Program
- Fund raisers included:- sale of Worlds Finest Chocolates, Raffle prizes included :- a night at Sheraton Towers plus \$100.00 dinner voucher at Carriages Grill, a \$50.00 voucher, and a \$20.00 voucher from a store of your choice. \$100.00 cosmetics from Nutrimetics
- Zoladex stories appeared in the newsletter.
- Grants were received from Queensland Health for

- 1) Organisational support: for use of rooms at Andrew House Wickham Tce where general meetings could be held in the hall. Also a photocopier, computer, software & printer
 - 2) Counsellor Training and Refresher Courses
 - 3) Information Brochures Grant. Thanks to Judy Murray author of “When a Dream is Shattered” for assistance in writing the brochures
- Support Group established – Bundaberg & Cairns
 - Contact established with Victorian Association at the 1st National Symposium held for their 10th anniversary.
 - Contact established with outside bodies to increase community awareness – Medical Benefits Fund, and Professor Carl Wood Chairman of Dept of Obstetrics and Gynaecology at Monash University.

1995

Committee:

President:	Trish McKenna
Vice president	Wendy Green
Secretary	Dianne Rippon
Treasurer	Jude Perryn
Minutes secretary:	Julie Watling,
General Committee Members:	Elsbeth Jeffery, Ann de Mattia, Angela Schramm, Kylie Webster

- Rockhampton & Ipswich Regional support groups established
- Support worker refresher course conducted by Ruth Bouma at Mt Ommaney Lodge.
- Guest Speakers – Chris Humphreys,- Natural Therapist on reflexology, Dr O’Connor treatment and Dr Bell Colorectal surgeon, Judith Thompson, Naturopath on Acupuncture & Chinese Herbal medicine.
- A video recording of Dr Carl Woods speaking about causes, treatments and signs of endo, shown at a general meeting.
- Endometriosis Research Group established by QUT & QMIR to look for cause of endo & genes. Members who had family members suffering from endo were invited to participate in the research.
- On 20th October a fundraising dinner was held at Alexandras at the TAFE Hospitality College at Coorparoo. Auction and raffle.
- A Fashion Parade – Helen McSwan
- The Christmas Raffle was a Stefans voucher, bookstore voucher & crocheted handkerchiefs.

1996

Committee:

President:	Trish Mc Kenna
Vice president	Wendy Green
Secretary	Melissa Dyson

Treasurer	Kylie Webster
Minutes Secretary	Elsbeth Jeffery
Membership Secretary	Angela Schramm
Newsletter Editor	Jude Perryn

- General Meetings:
General discussion on GnRH Analogue drugs – Synarel & Zolodex
Joy Byrne took us through yoga movements
At the Oct 15th meeting Julie Veer introduced us to the ancient Chinese art of medical Chi Qigong.
Dr David Molloy spoke on Endo and Fertility
- Joy Bryne ran a series of yoga classes in the hall. One night the lights were turned off for a meditation segment when they were turned back on we found that we had been joined by some unwelcome visitors and Debbie Scarlett received a fright to see a cockroach walking on her leg.
- We received media coverage by Christine Davis on Brisbane Extra - 28 calls next day. Melissa Dyson was interviewed by the ABC & The Courier Mail.
- Harriet Perryn won the 1st prize in the Mother's Day raffle of a weekend at Treasury Casino. Other prizes included Accommodation at ANA Gold Coast, Dockside Apartment Hotel and The Park Royal Hotel. Mary Ryan bookstore voucher and Arnotts biscuits.
- The fundraising Chocolate drive was a success.
- In December the Association vacated the rooms at St Andrews as funding had run out. After much searching, an offer was received to share a room at St Albans Church, Auchenflower at no cost. Tim Jeffery and Michael Perryn were thanked for their help in moving the furniture and large photocopier down the stairs at St Andrews and into St Albans.
- Regional support groups were established at Hervey Bay & Townsville. Library books were purchased to send to each regional support person.
- With assistance from the Association a QUT student, Lucille Lim produced the brochure "How you can cope with Endometriosis" as one of her assignments.

1997

Committee:

President:	Trish McKenna/Ann Belby
Vice president	Wendy Green
Secretary	Melissa Dyson
Treasurer	Elsbeth Jeffery
Membership Secretary	Jude Perryn
Newsletter Editor	Bronwyn Biddulph & Gerry Murphy
Support Worker Coordinator	Ann Belby
Librarian	Melissa Dyson

- Committee meetings were held in the church until August
- David Hawkins from Searle spoke on Synarel on June 17th
- 19th August information night on aromatherapy – by Jo Dalglish
- Endo Awareness night Fri 12th September Prof Carl Wood spoke on the topic "FACTS, FICTION, FALLACY, FANTASISES" at Mayne Medical Centre

- In May a trial Endometriosis Clinic was held at Holland Park. Appointments required. 3 or 4 to be held during the year with Prof Wood travelling up from Melbourne for each one.
- The Mothers Day raffle prizes were – Emma Page Jewellery. \$40.00 gift voucher from Myer, \$25 book voucher from Aust Book Centre, Sumner Park.
- A weekend Support Worker training course was run on 19th/20th July by Val Summerville
- Melissa Dyson spoke at a Women’s Health Queensland Wide forum. Bronwyn Biddulph told her “I Story”
- Due to personal reasons the president, Trish McKenna resigned.
- The brochure sub committee completed “Endo and Hysterectomy”, “Endo and Teenagers”, Endo and Natural Therapies”. “Endo and You” was edited & reprinted
- A donation was received from the Miss Personality Quest entrant from The Gap
- QIMR achieved funding for the research to find the genes responsible for endometriosis. 400 pairs of sisters and their parents were required
- In August the Association moved premises to an area at Mr Fixit, Sumner Park.

1998

Committee:

President	Ann Belby
Vice president	Ann de Mattia
Secretary	Kharla Kedgley
Treasurer	Jude Perryn
Membership Secretary	Mary-Ann Tsuji
Newsletter Editor	Bronwyn Biddulph & Gerry Murphy
Support Worker Coordinator	Gerry Murphy

- In March Ann de Mattia spoke at Women’s Health Conference on Endometriosis and Cervical Cancer at Mater Education Centre
- Discussion evening – Zoladex
- Clinic support at Wesley Hospital were held once a month
- Credit card facilities were introduced
- August - 10th anniversary celebration “10 years and still moving forward”
 - Ann de Mattia ABC on air interview, Quest newspaper interviewed Elspeth Jeffery for Southside News.
 - Seminar and presentation of ten, 10 yr memberships by Val Summerville
 - Ann de Mattia spoke on her history
 - Dr K Forbes on Endometriosis
 - Dr Susan Treloar on QIMR research
 - David McLeod spoke on Alternate Therapy treatments
 - Raffles – Couran Cove Resort, O’Rielly’s Rainforest Guesthouse, Happy Valley Vineyard Retreat, Dianne Rippon & Emma Page Jewellery
 - Thanks Bardon Conference Centre
 - Donations SNS, Mediherb, QFG, Qld, IVF Services Wesley IVF Unit, Time Off Magazine and The Gap Tavern

- October general meeting guest speakers Dr Glen Sterling on symptoms, signs, diagnosis & treatments and Dr Jim Nicklin on bowel symptoms
- The Endometriosis Clinic moved to Wesley Hospital with Jo Tyson co-ordinating the bookings.
- Ann de Mattia spoke at Healthwise Clinic at Wesley
- 6 support workers attended the ‘Endometriosis Fact & Fallacies’ conference facilitated by Drs John & Janet Allan at the Wesley Hospital
- Fund raising Shopping Tour was held in conjunction with Friends of QFG

1999

Committee:

President:	Bronwyn Biddulph
Secretary:	Karen Stevenson
Treasurer:	Jude Perryn
Membership Secretary	Mary-Ann Tsuji
Newsletter Editors	Gerry Murphy, E. Jeffery
Newsletter Committee	D Scarlett, M Sandalj
Support Worker Coordinator	K Reilly
General Meetings:	Roseanne Mitchell, A Crawford
Librarian:	M. Hardham (Dyson)

- Introduction of sub committees
- Focus on Endo & Food in newsletters
- Addition of recipes suitable for endo sufferers to newsletters
- Val Summerville conducted Support workers Counselling course
- Ann Black (de Mattia) spoke at a high School and Gerry Murphy at the Mater Hospital
- General meetings were held at the Graduate School of Medicine. Guest Speakers were:- May – Dr John Allen – Endometriosis and Fertility
August - Dr G Tronc & Prof C Wood – Endo and Polycystic Ovaries
- Brisbane Endometriosis Clinics co-ordinated by Jo Tyson continued at the Wesley Hospital. Catherine Hughes, Acupuncturist & Herbal Medicine clinician, worked with a support worker at the clinic.
- A meeting was organised in Barcaldine with President Bronwyn Biddulph attending. Thanks to Nicole Cook & Netta Dean for co-ordinating the event. The meeting was a huge success with some participants driving many hours to attend. The women were so happy to talk with Bronwyn Biddulph that the meeting went hours over time. Regional ABC interviewed Bronwyn and advertised the event.
- Coffee Club Meetings Commenced

2000

Committee:

Co -Presidents:	Jude Perryn and Gerry Murphy
Secretary	Karen Stevenson
Treasurer	Kim Goodwin

Membership Secretary	Gary Scarlett
Newsletter Editor	Espeth Jeffery, Gerry Murphy, Maria Stjepanovic, Debbie Scarlett
Support Worker Coordinator	Bronwyn Biddulph
Librarian	Jaimey Bampton
Teenager Support	Ann Belby
Clinic Support	JoAnne Tyson
Public Speaking	Ann Black (de Mattia)
General Meetings:	Anda Davies
Fund raising	Kim Goodwin, Sue Poon, Debbie Scott

- General meetings
February - Dr Jim O'Callaghan spoke on Pain Management
May – “From a Male Perspective” – Sid Everingham
August - Charles Farrugia muscle relaxation technique
- Commencement of Teenagers with Endometriosis Connect (TEC) instigated by Ann Belby
- The 1st Trivia Night was held at St Lukes Anglican Church Hall Tarragindi in May. Over 80 people attended. Over 100 people attended in October.
- Coffee club meetings continue to be well attended
- A Support Workers Training course with Val Summerville was held.
- The Association was involved in organising the 1st Nationally Registered Endometriosis Awareness Week. Our meeting was held on 31st October at the Bardon Conference Centre. Guest Speakers were Glen Stirling, M Condon (Infertility Psychologist), Susan Treloar. Financial support was received from Dr Grahame Tronc & Dr Julie Lindstrom
- QMIR – research phase 2 a new study on the effect of environmental factor by Tanya Bell. Members were involved in the study. Committee members were invited to attend Tanya's presentation of her findings.
- The Brisbane Endometriosis clinics continued at the Wesley with Co-ordinator Jo Tyson
- Coffee mugs were printed with the Association's Logo and the slogan “Help End Endo” to be sold to raise funds.
- A grant was received from Jupiters Trust for upgrading office equipment – 1 pager, 4 fax machines, 2 printers.

2001

Committee:

President:	Kim Goodwin
Secretary	Darlene Scott
Treasurer	Karen Stevenson
Committee Advisor:	Judy Perryn
Membership Database	Gary Scarlett
Newsletter Editor	Espeth Jeffery, Gerry Murphy, Debbie Scarlett
Support Worker Coordinator	Bronwyn Biddulph
Librarian	Jaimey Bampton
Meetings co-ordinator	Tanya Diddlick
Teenager support	Anda Davies

- Jude Perryn was awarded Life Membership at the Annual General Meeting
- Guest Speaker Debbie Eales, physiotherapist spoke on Pelvic floor Exercises at the February meeting.
- June – Jude Perryn was awarded an OAM in the Queens Birthday Honours List
- The first Trivia Night was held in St Luke’s Hall Tarragindi in May raised over \$1,000.00 - 100 people attended. The monster raffle had 200 prizes. The next trivia night in October was attended by Robin Bailey from B105. The station also gave the event community awareness coverage
- During Endo Awareness Week in July Kim Goodwin & Dr Susan Treloar were interviewed on the Bert Newton Show – Good Morning Australia Awareness week activities also included an interview on B105, Tour of QMIR and involvement with the ECCA Seminar
- In August our Coffee cups and & cookbooks were advertised on the TV show The Panel –this was a successful venture
- In October Guest Speaker was Kim Kempthorne, Natural Therapist from Southern Cross Natural Therapy Centre Underwood
- Members participated in Pain Research by Helen Hartley
- TEC continued
- Dr Dan O’Connor was awarded a Churchill Fellowship to “Search for the triggers connected with Endo”
- Saturday Coffee Club continued
- Research Update on St John’s Wort for Women appeared in Health Qld Wide Health Journey
- Member Katrina Dunks participated in the USA “Endo Walk for Awareness”
- The Association started selling entertainment books as a fundraiser.
- An “I Story” re how helpful the association was appeared in the newsletter.

2002

Committee:

President:	Kim Goodwin
Vice president	Jude Perryn
Secretary	Tanya Diddlick
Treasurer	Darlene Scott/Corinne Hobin
Committee Advisor:	Judy Perryn
Membership Database:	Gary Scarlett
Newsletter Editor	Jo Hope/N Holmes
Support Worker Coordinator	Bronwyn Biddulph/Elspeth Jeffery
Librarian	Karen Stevenson/Darlene Scott
Committee Advisor	Jude Perryn
Teenager Support	Anda Davies/Melissa Gibson
Website	J&J Perryn

- General Meetings: March – Younger women’s Health Seminar Wesley – Dr G Sterling contraception, Dr S Baines signs, symptoms & diagnosis, Dr Sue Treloar research
- Fundraising:- The Bulb drive very successful, a new fundraising activity was hand made cards

- The Coffee Clubs continued
- The Trivia night in May had over 100 attendees. The Halloween theme at the October Trivia night was very successful. John Perryn produced labels with a Halloween theme for clean skin bottles of red and white wine. The “Bloody Good Wine” was a sell out. The evening raised \$1400.00
- During National Awareness Week Kim Goodwin, Sue Poon & Dr Susan Treloar were interviewed for the ABC news on research
- New Stanthorpe and NSW regional contact
- TEC continued and High School visits were introduced
- A Poem by Stephanie Maddison, member and a journalist with the Courier Mail appeared in the newsletter
- A Counselling course was run on 2nd November by Val Summerville
- The NSW Endometriosis Association closed.
- Jude Perryn & Kim Goodwin were invited by, Dr Geoff Reid & Dr Julie Lindstrom to watch operations at the Wesley Hospital to see new spray gel in use (it taken off the market in the USA in 2003 due to problems it caused)
- Members were invited to participate in a study through Murdoch University WA re emotional consequences that stem from infertility
- Insurance issues –Public Liability costs soared.
- A NAB interview on Endometriosis went to 25000 staff members. Huge response, 1 women set up a raffle for the association which raised \$350.00

2003

Committee:

President:	Kim Goodwin
Vice president	Darlene Scott
Secretary	Corinne Hobin
Treasurer	Jude Perryn
Committee Advisor;	Judy Perryn
Newsletter Editors	Corinne Hobin & Gary Scarlett
Support Worker Coordinator	Elsbeth Jeffery
Librarian	Darlene Scott
Teenager	Melissa Gibson
Membership	Gary Scarlett
Website	Tanya Didlick

- Ms Paula Duncan offered to be the Association’s Patron
- In August a Formal Dinner and Auction was held to celebrate the Associations 15th Birthday. Sydney guests included Paula Duncan, Cornelia Frances, Danielle Paull, and Andy Lopez. Entertainment was provided by Liz Taylor, Karen Schaupp, Trio J3 and Flemenco Dancers. Dr Tronc was a major sponsor donating \$10,000. The System Works Pty Ltd was a Bronze Sponsor donating \$1,000.
- Fundraising events were the Trivia nights in May and Oct, sale of bulbs and entertainment books
- The business cards, brochures and letterheads were reprinted
- Darlene Scott again organised the questions for trivia night

- The Association participated in the Ecce Seminar: Dr Tronc – endometriosis and its treatments, Jocelyn Klug relationship counsellor & sex therapist, Trish Wilson counselling endometriosis sufferers, Lis Isenring – dietician.
- Kim Goodwin attended the AGES (Australian Gynaecological Endoscopy Society) pelvic pain symposium at the Gold Coast
- Updates were received from QMIR re medical research
- Coffee club continued monthly
- Interviews were held with a with medical student as part of their training.

2004

Patron: Paula Duncan

Committee:

President:	Kim Goodwin
Vice President:	Judi Cogliati
Secretary	Darlene Scott
Treasurer	Jude Perryn
Committee Advisor;	Judy Perryn
Newsletter Editor	Katrina Jeffery, Kim Goodwin, Debbie Scarlett
Support Worker Coordinator	Darlene Scott
Librarian	Darlene Scott
Teenage Support	Melissa Gibson
Membership Database	Gary Scarlett
Fundraising:	Kim Goodwin, Elspeth Jeffery, Kylie McCluskey, Judi Cogliati, Jo Dickson
Ball Committee:	Jude Perryn, Kim Goodwin, Elspeth Jeffery, Melissa Gibson, Kylie McCluskey
Grant applications	Jaimey Bampton
Website Updates	J&J Perryn

- A Counselling course was held on Saturday 17th July
- The Association won Workplace of the Day run by radio station B105. The interviewer couldn't say endom..... so the ladies kept saying it for him 30 times...
- National Endometriosis Awareness Week Seminar was held on 23rd August at Wesley Hospital. Speakers were;- Dr Gino Peccaro spoke on Endometriosis and the couple, Endometriosis and fertility – Ways to cope. Dr Graham Tronc, Dr Sue Treloar, & David McLeod, Naturapath.
- The coffee clubs continued.
- A visit was made to Fernwood Gymnasium, Carindale.
- There were 3 high school visits.
- May Trivia nights raised \$800.00 with 50 people attending. Oct raised \$1504.00.
- Judi Cogliati painted a banner to be used at functions, meetings etc.
- It was decided to adopt a stylised blue butterfly as our signature.
- The No Knickers Ball was held on Aprils Fool Day at the Brisbane Mariott Hotel. Entertainment was provided by Vanetta Fields, Kitana (singer song writer) a fashion Parade with underwear from Holeproof, the Brisbane band Crave, Belly Dancing Troop (member Jo Dickson one of the dancers) Live and silent auctions. Sponsors

were ECCA, 4BC radio, Marriott Hotel & Holeproof (who donated boxes of “No Knickers” underwear).

- Paula Duncan’s brother was involved in a new venture selling “Macupants” and wanted the Association to promote them. The Association declined.
- Sale of Spring bulbs for fundraising
- The Association purchased a second hand digital photocopier

2005

Patron: Paula Duncan

Committee:

President:	Judi Cogliati
Vice president	Kim Goodwin
Secretary	Darlene Scott
Treasurer	Lisa Blackburn (now Sandaver)
Committee Advisor:	Judy Perryn
Newsletter Editor	Corinne Harrison
Support Worker Coordinator	Darlene Scott
Librarian	Elsbeth Jeffery
Membership Secretary	Darlene Scott
Website updates	J&J Perryn
Fund raising	Judi Cogliati, Kim Goodwin, Kylie McCluskey, Jo-Anne Dickson, Jude Perryn, Corinne Hobin (Harrison)
Grant Applications	Judi Cogliati, Kim Goodwin, Michelle Lindley,

- It was decided to hold Saturday Coffee Club at different suburbs each month to attract new members. Venues to include: Ipswich, Cleveland, Redcliffe, Logan Hyperdome and Stafford City.
- May –Endometriosis Awareness Week - ECCA seminar – Dr Susan Evans author of Endo and other Pelvic Pain visited Brisbane for book signings and spoke at the seminar, along with Dr Susan Treloar & Dr Grant Montgomery and David McLeod
- A questionnaire was sent to Obstetricians/gynaecologists in order to improve our information base. Successful
- Fund Raising trivia nights raised around \$2,000 in both May and October.
- A Gala event to be held in August was cancelled due to lack of numbers
- Judi Cogliati introduced a Craft Circle. A stall was held at the Cleveland markets
- A Charity Auction and Xmas Party was held at Dicey Rileys, Garden City in November - \$2,000.00 was raised
- The Association joined the Asia Pacific Endometriosis Alliance (APEA)
- Christmas cards were hand made by members as a fund raiser.
- Members and guests picnic was held at Southbank Parklands
- The selling of Entertainment books, Qld Fruit & Nut, Cookbooks, Coffee Mugs and Christmas cards continued as fundraisers.

2006

Patron: Dr Susan Treloar PhD

Committee:

President: Judi Cogliati
Vice president Michelle Lindley
Secretary Jude Perryn
Treasurer Lisa Sandaver
Newsletter Editor Annie Niemiec
Support Worker Coordinator Joanne Dickson
Librarian Elspeth Jeffery
Membership Secretary Sue Jopling
Website updates Judi Cogliati
Fund raising & grant applications: Michelle Lindley

- The Endometriosis Awareness Week changed to March to align with International Awareness Week in the Northern Hemisphere.
- An Awareness Week seminar was held at Wesley Hospital Auditorium. Guest speakers were:
 - Dr Gino Peccoraro - New diagnosis & Treatment
 - Jocelyn Klug - Endometriosis & Relationships
 - Jon Wardle - Naturopathic Treatments
 - Lisa Sandaver - Muscle Care & general fitness
- We were saddened to hear that our sister group the Victorian Endometriosis Association had folded.
- Support Worker training session was held with facilitator Trish Wilson.
- Fundraising events included:
 - Trivia nights in May and October
 - The sale of Cookbooks & Coffee Mugs
 - Qld Fruit & Nuts
 - Tea towels & Entertainment books
- In August we were saddened by the sudden death of past president Kim Goodwin. Who could ever forget Kim's enthusiasm and dedication. The Association's library was renamed The Kim Goodwin Memorial Library in recognition of her contribution.
- A Grant was received at the end of 2006 from the Community Benefit Gambling Fund to formulate a Strategic Plan for the next 3 years.
- Coffee Clubs were suspended due to lack of attendees

2007

Patron: Dr Susan Treloar PhD

Committee:

President: Lisa Sandaver

Vice president	Michelle Lindley
Secretary	Mia Bowen
Treasurer	Anthony Netting
Newsletter Editor	Annie Niemiec
Support Worker Coordinator	Michelle Lindley
Librarian	Elspeth Jeffery
Membership database	Sue Jopling
Website updates	J&J Perryn
Grant Applications	Michelle Lindley

- A sub committee was formed to work with Tahlia VanGils from Volunteering Queensland to formulate the strategic plan.
- Fundraising activities continued to bring in much needed funds
 - Trivia nights x 2
 - Entertainment books
 - Cookbooks & Coffee Mugs
 - Qld Fruit & Nuts
 - Tea towels
- Anthony Netting and Sue Jopling relocated to Tasmania. Jude Perryn stepped in as relief Treasurer until the AGM.
- The 20th Anniversary celebration sub committee was formed.

2008

Patron: Dr Susan Treloar PhD

Committee:

President	Judi Cogliati
Vice president	Jude Perryn
Secretary	Libby Needham
Treasurer	Katrina Dunks
Newsletter Editor	Mia Bowen & Lisa Sandaver
Support Worker Coordinator	Anda Davies
Librarian	Elspeth Jeffery
Web mistress	Judi Cogliati
Support Workers	Judi Cogliati, Anda Davies, Katrina Dunks, Elspeth Jeffery

- Judi Cogliati and Jude Perryn self funded their attendance at the 10th World Congress on Endometriosis in Melbourne
- Throughout the congress it was obvious that that there is a section of the medical profession that recommends surgery and another that favours medical treatment. It was obvious that there is not just one mode of treatment. It is still important for a woman with Endometriosis to find a Doctor who is up to date with treatment options and who allows the patient to be involved in their treatment choices.
- We were advised that no new studies had been commenced between 2007 and 2008.
- The newsletter editors gave birth to boys within 3 weeks of each other.
- Celebration activities for the 20th Anniversary were finalised.

OUR POETS

The following poems have been reproduced as submitted by the authors.

ENDO

Sometimes the pain is too much,
You feel out of touch,
With people.
Because people don't always understand,
For Endo doesn't always command,
Much recognition or attention,
"It can't be that bad",
They say.
It's comments like these that make you frustrated,
Sad.

If only they knew,
What we've been through,
They might be more sensitive to our plight,
And though there is a light,
At the end of the tunnel,
Half the flight,
Is the journey there.
Though there are some rocks of support,
Sufferers still report,
Many people still haven't heard of this malady.

Endo must be fought,
And more awareness brought,
So the disease can be examined and fully understood,
In order to help our Endo sisterhood.

By member Stephanie Madison 2002

Kim's Light Shines On

When we see a candle burning,
We can feel its warmth and light.
It can brighten even the darkest day,
And bring hope to the longest night.

When someone lights a candle for us,
We can see it up close or from afar,
Its light is like the sun's beautiful rays,
Or the night sky's shiniest star.

When someone special lights a candle,
It touches the life & heart of both you and me,
And through their caring and generous heart,
Forever understood you will feel and be.

Kim, you not only lit a candle
For all Endo women to see.
You kept it burning ever so brightly,
Bringing hope and courage to many others & to me.

Your candle light gave so many things,
To so many women in great need.
From a much needed listening ear,
To sharing valuable information for them to read.

Your willingness to reach out so wholeheartedly,
Without a second thought,
Your kindness and compassion,
Are life's gifts, not so easily bought.

Your determination to always do your best,
No mountain was ever too steep to climb,
Your endless tenacity and enthusiasm,
We saw time after time.

The special thing about a candle's glow,
Is long after the candle has been blown out,
Its light and hope and spirit continue on,
Its treasured gift can be felt still all about.

When you joined our Endo group,
It became a cause so close to your heart,
Your ability to fundraise and make things happen,
Was truly amazing, right from the start.

Kim, please know your caring legacy and commitment
To the Endo Association will live on,
In memory of your devotion to our group
That I know you felt so proud to belong.

Even though you have now journeyed on,
To God's peaceful love & resting place,
What will never, ever leave us
Is your infectious laughter and your smiling face.

Written by Bronwyn Biddulph
(On behalf of the Endometriosis Association)
6/8/06

THE LIGHT AT THE END OF THE TUNNEL

I have to believe there's a light at the end of the tunnel, especially when I can't take it any more. The past three years I've asked myself a thousand times, what is this happening for?

First, there was the original diagnosis. I thought, this will be OK. It can't be all that bad – this endometriosis – maybe it will go away!

But go away it didn't, in fact the relentless onslaught had just begun. I felt trapped within this damaged body, there seemed nowhere I could run.

It was the start of many tearful days, that eventually turned into three difficult years. It was the start of a life of uncertainty, with many broken dreams, hopes and fears. There's the constant disruption to my career, and there's always the financial strain. Wondering whether a future partner will be accepting of rough times and pain. Then there's the difficulty sharing your story with family who can't believe what they've been told. Of dealing with their shattered dreams, of the grandchildren they will never hold. It has touched and changed every part of my life, things will never be as they were before. You learn to live with it day by day, not knowing what's in store.

You try to adjust your life around it, but sometimes it's hard to bear. When you feel the pain and suffer the losses, I feel at times, that it's really not fair.

It's an endless search for answers, going from one treatment to another.

You recover from numerous surgeries and medications wondering "Will I ever fully recover?". Mine began in my reproductive system, spread to other places and even affects my nose. It was recently found in my chest and liver, where it will go next – nobody knows. I feel the fear every day, but also feel the hope that with inner strength and other's wonderful support, no matter what I'll always cope. Endometriosis challenges the deepest part of you, the part you never knew was there, but it can bring out the best in others when it sends you into frequent despair. I feel I'm a never ending story now, my options for the future are very few. Either a hysterectomy or live with it is about all that I can do. The answers never come easy, it's a case of I'll be damned if I do or if I don't.

But know one thing for certain, give up and lose courage, I won't. Because you see my life is precious, though debilitating and hard it may be and whether I look through eyes of grief or glory, will always be up to me.

Bronwyn Biddulph

THE FUTURE

World Congress on Endometriosis 2008

The Art & Science of Endometriosis

A report by Judi Cogliati & Jude Perryn

On the 10th March we travelled to Melbourne to represent our Association at the tri-annual meeting of the International Endometriosis Community. This International Congress brings together researchers, specialists, support organisations, pharmaceutical companies and all interested organisations and persons in a single cause – Endometriosis.

With support groups from The Netherlands, America, England and Puerto Rico attending we made many new friends. We met socially on two occasions and discussed the different challenges that we all faced in providing assistance to those in need. Whilst at the congress we renewed contact with long term associates and made new locally based contacts.

Even though ours is a small group, we are recognised as having made a major contribution to endometriosis research through our involvement with the Genome Project with Queensland Institute of Medical Research (QIMR) and Oxford. There were many papers presented at the congress that were related to research taken from the data collected from the sampling done by Dr Grant Montgomery and Dr Sue Treloar's team at the QIMR – Oxford Genome project. All our donor members and families can be very proud of their contribution to this ongoing research effort which has enabled so much research into endometriosis.

The Congress was a great way to make contact with many local doctors and to have our Association represented in the world of endometriosis. Our group is currently the only volunteer support organisation that is operating in Australia. One good thing to come out of the event is that we found some great new contacts and there has been an overwhelming surge of agreement that there needs to be a National Endometriosis Organisation. Unfortunately, due many factors including conflicting legislation for funding, legalities, and operations in each State, this is largely a dream that may come at some time in the future.

There were many interesting issues to come out of the congress that we would like to share with you. Over the coming weeks we will be hard at work taking all the “best bits” from the program and condensing them into a special edition of our newsletter.

The overall content of the congress, whilst interesting, did not give us any great revelations with sure-fire treatments or cures for endometriosis. It continues to confound the best medical and scientific minds and there is a multitude of research being conducted including investigation as to why it happens, how it works, how best to treat it.

One ground breaking piece of news was a “pap smear like” test that is very effective in diagnosing women with endometriosis. The technology has originated from Australia and, if all goes well, may be ready for trials in around 5 years. It is early days so we cannot expect too much too soon but it is a step in the right direction with early diagnosis. There may be some scope for our Association to be involved in the research with this project in the future. We will keep you informed as we hear further news.

It was made clear that laparoscopy is still the “Gold Standard” for diagnosis of Endometriosis.

We were both personally very impressed with the work of the NZ Endo group and the program Deborah Bush has developed with teens in the South Island of NZ. If you have the opportunity, take a look at their website www.endo.org.nz – it is designed for teens and young women and is delivered in a positive way.

During the Congress we had a meeting with Deborah to discuss the program. If the Association could secure funding for a pilot program, teamed with a research project, this may be an interesting way of educating teens about endometriosis. If this is successful, there may be scope for further funding for this type of program in the future. We would need government funding and support from other groups of interested doctors and researchers to enable this to happen.

All costs associated with attendance at the Congress were personally paid for.

