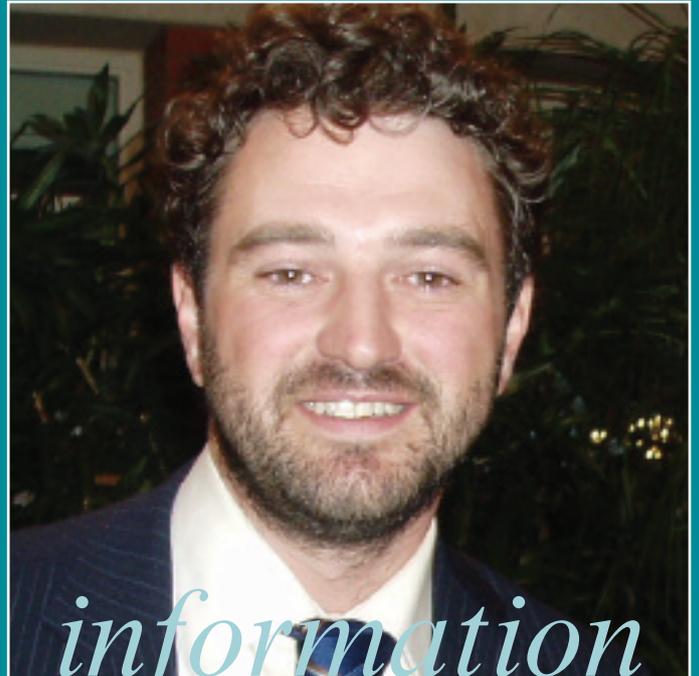


THE MISCARRIAGE ASSOCIATION

ANNUAL REPORT 2006–2007



support



information



awareness



good practice

**Miscarriage can be a very unhappy,
frightening and lonely experience.**

**The Miscarriage Association acknowledges
the distress associated with pregnancy loss
and strives to make a positive difference
for those it affects.**

The Miscarriage Association



acknowledging pregnancy loss

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The Miscarriage Association is a registered charity, number 1076829
and a company limited by guarantee, registered in England & Wales, number 3779123

foreword



Miscarriage is special because, until it happens to you, you don't know how you will feel. And responses vary.

Some people grieve immediately, others take time to acknowledge what they feel and to express it. But whether you experience miscarriage yourself or have to watch someone you love suffer because of it, your world is changed.

There is a current belief that we are much more open about emotional issues now. Just because you can use the words, it doesn't mean you can claim the feelings.

But even if it's true, many people are only more open out of their own experience of disappointment and loss, the feeling of being mistaken, getting it wrong, being a failure. And anyone who has had a miscarriage or watched someone they love have a miscarriage has felt all of that, and betrayed by their body, and alone.

The Miscarriage Association came into being in response to those feelings, to help, support and inform. In distress, we need to invest in the idea that something better can come out of something unhappy. We need to be able to ask questions and get answers. We need to be able to help others, as well as to be helped.

Sometimes the shortest words pack the hardest punch, like CARE, a word indelibly associated with The Miscarriage Association and clearly demonstrated in the following pages. I am proud to be one of its patrons.

A handwritten signature in cursive script that reads "Anna Raeburn".

Anna Raeburn

Although miscarriage is sadly all-too-common, it is still something of a taboo, and this can leave people feeling very alone and unsupported. The Miscarriage Association provides support, understanding and, above all, a listening ear to anyone affected by pregnancy loss.



Usha Harte:

'People will cross the road to avoid you if you have had a miscarriage.'

I always knew I wanted a big family, but after 15 years and eight pregnancies, Paul and I have just two children – Fergal, aged five, and Preeya, three.

My first miscarriage was very early. I was sent away with no support or even basic information

and went straight to work, where I got more help from my friends than I had from the doctor.

I had five more miscarriages over the next 6-7 years. Probably the worst was a missed miscarriage, where you go for a scan and there is no heartbeat. That is unspeakably dreadful because you feel that as a mother you should know. I was on my own at the time, but there was no follow-up and no one contacted me with information, support or advice.

The lack of support I had from professionals makes me angry to this day. Fortunately, though, I was referred to a wonderful nurse for counselling and it was in her office that I first saw the Miscarriage Association leaflets.

After the sixth miscarriage, we moved and decided to get on with our lives. But I did get pregnant again and this time the little fella decided to hang in there, although right up to the birth I didn't really believe it was happening.

Miscarriage is the final taboo. You can talk about death in almost any other context, but people will cross the road to avoid you if you have had a miscarriage. It is a bit like a mission with me to help people access the support The M.A. has to offer.

“ I couldn't stop crying when I first found out, but since I had the operation I have just felt numb and don't know how to feel. People say “Well at least it wasn't a proper baby”, which is just an awful thing to say – it was still my baby. ”

“ Thank you so much for giving me the chance to have the conversation I so needed to have, something that no-one else has given me. ”

Providing support in 2006/2007:

Staffed helpline

- We provided a staffed helpline five days per week, providing a swift, sympathetic and informed response to 8,400 letters, calls and e-mails requesting support and information.

Support volunteers

- We coordinated a UK-wide network of 98 telephone contacts, including 23 new volunteers, and 30 local support groups.
- Fifty-six contacts provided support on 24 specific areas of pregnancy loss (such as recurrent miscarriage and ectopic pregnancy).
- Twenty-two volunteers staffed an out-of-hours helpline, offering support at evenings, weekends and Bank Holidays.
- Eight regional co-ordinators helped us select, support and mentor all support volunteers.

Newsletter and website

- We published a quarterly newsletter, a source of support, information and comfort for our members. We posted selected items on the website, which also contains personal reflections and poems.

Accessibility and equality

- We ensured that venues and facilities for central M.A. events were accessible to people with disabilities and continued to develop distance learning facilities for potential and established volunteers to reduce barriers to volunteering.
- All of our leaflets are available in large print and on our website; and staff are familiar with RNID's Typetalk service for deaf and speech-impaired callers.
- Staff and volunteers were able to offer support in 9 languages other than English; and we began a project to investigate the needs of other non-English speakers.

Recognition

- The Miscarriage Association was highly recommended in the GlaxoSmithKline IMPACT Awards.

Those who have suffered pregnancy loss are often desperate to find out why it happened and what might happen in the future and it can be difficult to know what information is reliable. The Miscarriage Association consults with experts so that we can provide clear and accurate information and we also promote further research into the causes and treatment of miscarriage.



Matt Wikeley:
'The Miscarriage Association leaflet made a big difference to us in Japan'

Emma and I were working in Japan in 2005 when she became pregnant, but we both spoke hardly any Japanese. When she went to hospital for a scan they sent a doctor with the best English they could find to tell us there wasn't anything there!

Another scan suggested it was a hydatidiform mole, where the pregnancy doesn't develop properly.

They said Emma would need an operation to remove all the dead cells. If that didn't work, she would need a course of chemotherapy, which was scary.

More in hope than anticipation, I googled 'hydatidiform mole' on the internet and immediately found a nice, clear leaflet by The Miscarriage Association. This made a big difference to us, first because it helped us fill in some of the information gaps and secondly because we were able to reassure family and friends and direct them to the same information.

We were told that if Emma's hormone levels returned to normal within a certain time everything would be fine. But after a few months the levels spiked again and Emma was advised to return to England for a course of chemotherapy. The treatment was a success and we have been told there is no reason why we shouldn't try again.

Last year I started jogging to get fit, then had the idea of running the London Marathon. I found out that The Miscarriage Association was looking for runners and decided to raise money – more than £2,000 in the end – for them. We had really benefited from their information and I wanted to support them to keep that information available for others.

“ I have recently had an anembryonic pregnancy which totally devastated myself and my husband. I was wondering what the chances of me having a normal pregnancy are in the future. ”

“ I run the Early Pregnancy Assessment Unit at St John's in Chelmsford. I went onto your site for some information re leaflets and I was really impressed with the information given. Well done with the new site. I recommend it on a daily basis and have always found it very helpful. ”

Providing information in 2006/2007:

Staffed helpline

- Helpline staff responded to a wide range of questions on pregnancy loss, providing clear information and clarifying confusion.

Leaflets

- We continued to publish a range of 19 leaflets on aspects of pregnancy loss.
- We sent over 57,000 leaflets by request to individuals and to hospitals and clinics and noted 2,300 visits per month to the leaflet pages on our website.

Accessibility

- We added another community language to our bi-lingual leaflets, which are now available in four Asian languages, Arabic and Turkish. We continued to offer a scripted dialogue about miscarriage on audiotape, in three Asian languages and in English.
- We began a project to research the need for materials in additional languages and formats
- We produced and began piloting a leaflet for people with learning disabilities and one for deaf people whose first language is British Sign Language.
- All leaflets are printed in clear typeface and are available in large print and on our website.

Website

- We completely revised our website to incorporate significantly improved content, design and accessibility. We initiated an improved website tracking system and by year-end were recording an average of 15,600 visits per month.

Research

- The research we commissioned into risk factors for early miscarriage was published in the International Journal of Obstetrics and Gynaecology, generating worldwide media interest.

When miscarriage is reported or portrayed in the media, inaccuracies and stereotypes are sadly common and men are often ignored. The Miscarriage Association works with print, broadcast and online media to make sense of news stories, to clarify myths and misunderstanding and to raise public awareness of the facts and feelings of pregnancy loss.



Nigel Martyn:
'I learned the hard way and would like to stop other men making the same mistakes'

When I was young football dominated my life and on the day my wife Amanda had her first miscarriage I went to the game even though she was complaining of cramps. She was devastated but I didn't really know what to feel or say.

Thomas was born the next year, but Amanda had to go through two more miscarriages and a life-threatening ectopic pregnancy before we had our daughter Fay.

The second loss followed a scan where they couldn't find a heartbeat. I am ashamed to say that I went off to play football while Amanda's parents dropped everything to look after her.

'The next time was different. I was on tour with Leeds when she started bleeding, and I jumped on a 'plane to be there for her. This time it wasn't just Amanda who was devastated, because it suddenly hit me that we were losing children.

After the ectopic pregnancy I was all for giving up, but Amanda's determination turned me around. The baby was expected in June '98, when I was due to be playing with England's World Cup squad in France, but I flew home for the birth and was back on a 'plane to France a few hours later.

After Fay was born I became a Patron of The Miscarriage Association, where my main concern has been to raise awareness of miscarriage among men.

Some men don't know what to say, so they say nothing – and then their partner thinks they don't care. I now realise that it was important for Amanda to know that I was hurting too and that we would get through it together. I learned the hard way and would like to stop other men making the same mistakes.

“ When we're planning storylines and writing scripts, we like to get things as right as we possibly can, although the demands of drama sometimes require us to take some licence. The M.A.'s expertise enabled us to look at a couple of options, of ways of progressing the story that were not too far beyond the realm of plausibility. We do not like to cheat our audience, and we feel we have a responsibility to portray issues truthfully. The M.A. has been extremely helpful as well as tolerant of the demands of a drama series – it was invaluable assistance. ”

Steve Byrne, Researcher, *Hollyoaks* (Channel 4)

Raising awareness in 2006/2007:

News & features

- We received wide coverage of the research we commissioned on risk factors for early miscarriage, giving ten interviews on television, radio and in the press; and we noted another 81 media reports worldwide on the findings
- We provided background information for a further 59 media articles, programmes and features, with help from 56 media interviewees who contribute personal reflections and experiences.
- We advised on storylines for five television dramas and noted that The Miscarriage Association's poster continues to be a regular background feature in the BBC hospital series *Holby City*.

Profile

- We worked with four other baby-loss organisations to promote National Babyloss Awareness Week, with remembrance events across the U.K.
- Staff and volunteers took part in a range of activities to raise awareness, including exhibition stands at a Health Fair targeting the Asian community and at the EIDO Patient Communication Conference
- Our supporters took part in more than 40 sponsored fundraising events, all of which raise awareness of the charity as well as funds
- We maintained an excellent internet profile, with links from other websites, so that we feature highly on the largest search engines.

The quality of care given to women by hospital and community health professionals can have a major impact on their experience and their memories of pregnancy loss. The Miscarriage Association promotes sensitive care for patients who miscarry, offering training and consultancy to healthcare professionals and supporting volunteers like Amanda to highlight patient perspectives.

Posed by model



Amanda Daykin:
'After a devastating experience, I'm helping my hospital provide better care and understanding for women who miscarry'

Nine weeks into my third pregnancy a scan showed no heartbeat and I agreed to go into hospital for "medical management". The whole experience was devastating.

I came away from that first visit with nothing except advice to look out for a "piece of gristle"!

After a long and traumatic day of being cared for by different nurses and being told "not to look", I was sent home with just a generic hospital leaflet which said nothing about the emotional after-effects. I went straight back to work, and for two weeks I battled with myself – why was I constantly crying, not eating, not sleeping? I broke down and sobbed my heart out – and that's when I rang The M.A..

I was put through to a telephone supporter who told me "allow yourself to grieve". After that I cried like I have never cried before and that really helped.

Eventually, I contacted the Patient Advice and Liaison Service (PALS) at my local hospital and said I would like to talk to them about my experience and what they could learn from it.

As a result I was asked to review the literature the Trust gives out to women who miscarry and to recommend which of The M.A.'s posters and leaflets they should stock. I have also helped to make the hospital more aware of the importance of listening to women and acknowledging them.

The Miscarriage Association really helped me and I have tried to give something back in the best way I could. I don't want anyone else to go through what I did.

“ I would like to thank you all for this wonderful day, I have learnt so much to take back to my colleagues and hope to make a real difference to some of our practices. ”

“ Just to say thank-you for a very informative study day, I felt it was probably the best study day that I have attended in my 25 years nursing and as a midwife too. ”

Promoting good practice in 2006/2007:

Conferences

- We ran a major conference for health professionals in association with the Royal College of Nursing and funded by the Department of Health.
- We contributed to the annual scientific meeting of the Royal College of Obstetricians and Gynaecologists Faculty of Family Planning & Reproductive Healthcare; to the Primary Care 2006 conference's Mother & Baby programme; and to the Royal Navy's Bereavement and Loss course.
- We worked with the Royal College of Nursing and the Institute of Cemetery and Crematorium Management to plan a series of workshops on the sensitive disposal of fetal remains.

Consultancy

- We provided expert opinion to four NHS Hospital trusts on the management of services for patients with pregnancy loss, especially relating to the disposal of fetal remains; and advised on establishing local support and information for patients in Brazil.
- We acted as advisors on six research proposals; and advised on patient information and professional guidelines for eight professional organisations and charities.
- We were invited to produce a tutorial on *Breaking Bad News* for the RCOG on-line training and tutorial system.
- We provided training for volunteers who want to represent the patient perspective on pregnancy loss in local NHS Trusts.

Collaboration

- We worked collaboratively with the Royal Colleges of Nursing and of Obstetrics and Gynaecology, the Association of Early Pregnancy Units and the charities ARC, the Ectopic Pregnancy Trust, Lifeblood and SANDS.

abridged accounts

1 April 2006 – 31 March 2007

	General funds £	Restricted funds £	Total £
Income:			
Donations & similar income:			
Membership fees & donations	18,056	1,030	19,086
Government grants	12,000	7,500	19,500
Other donations & grants	52,927	7,080	60,007
Branch income	–	7,013	7,013
Activities to further the Charity's objects:			
Sales	37,462	–	37,462
Conference & AGM fees	2,560	–	2,560
Activities to generate funds:			
Fundraising activities	52,243	–	52,243
Sales	3,102	–	3,102
Interest received	10,258	–	10,258
Total income	188,608	22,623	211,231

Expenditure:			
Cost of generating funds:			
Fundraising	30,291	4,739	35,030
Charitable expenditure:			
Service provision	107,224	10,784	118,008
Governance	37,478	252	37,730
Total expenditure	174,993	15,775	190,768
Net surplus/(deficit)	13,615	6,848	20,463

BALANCE SHEET

Fixed assets		2,669
Current assets		265,480
Total liabilities		(8,740)

Net assets		259,409
Represented by:		
Brought forward from 2005/06	221,622	17,324
Net surplus 2006/07	13,615	6,848
Balance carried forward	235,237	24,172
		259,409

This financial statement has been agreed by Mazars LLP as being consistent with the full financial statements for the year ending 31 March 2007. These were prepared in accordance with the Statement of Recommended Practice Accounting by Charities (revised 2005) and receive an unqualified audit opinion.

These summarised accounts may not contain sufficient information to allow for a full understanding of the financial affairs of the charity. For further information, the full annual accounts, the auditor's report on those accounts and the Trustees' annual report should be consulted. Copies of these can be obtained from The Miscarriage Association, c/o Clayton Hospital, Northgate, Wakefield WF1 3JS.

The full accounts were approved on 2 September 2007 and have been submitted to the Charity Commissioners.



Barbara Hepworth-Jones (Chair)

Auditors & accountants

Mazars LLP
Mazars House
Gelderd Road
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Cooperative Bank
Providence Street
Wakefield WF1 3BG

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West Malling
ME19 4TA

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Wobaston Road
Wolverhampton WV9 5HZ

reviewing our finances...

The Miscarriage Association continued its policy of managing its resources carefully in the year to 31 March 2007, enabling it to maintain a high level of service provision and to make provision for the future. This was achieved both through the support of our donors, members and friends and by managing The M.A.'s limited resources with great care.

During the year we noted growing income from general donations and grants, especially in general (unrestricted) income, which increased by £19,000 on the previous year. We also increased income from a range of fundraising activities, particularly the London Marathon. In contrast, income from government grants, membership fees and members' donations was less than in 2005/06. We also noted a drop of 11% in income from sales of leaflets to hospitals and clinics, almost certainly due to NHS financial constraints, and this is likely to be a continuing trend.

We continued to maximise the value of all of our funds with a mix of instant access and high interest savings accounts. The combination of earned, investment and fundraising income constituted 56% of The Miscarriage Association's general (unrestricted) income for the year.

Restricted income during the year was for three specific projects, two of which will be completed only in 2007/08. It also included branch income, and it should be noted that branch funds, which are incorporated into these accounts, are held and used by those branches alone.

As always, the generously donated services of all of our volunteers enabled us to keep the costs of providing direct charitable support relatively low, so that service provision accounted for just 62% of our total expenditure. This represents an estimated saving of 46% of service provision and support costs. We spent slightly more on fundraising than in the previous year, although this was more than compensated for by increased income from donations and fundraising events. The costs of governance, including legally required meetings, reports and accounting, constituted 20% of expenditure.

In general, the financial statements show a surplus of general funds for the year, which has enabled us to increase our General Reserve Fund and to designate some of these General Reserves for key projects where time-limited restricted funding has ended. The restricted fund balance carried forward at the year-end is for specific projects only.

The Miscarriage Association continues to develop its services in response to both continuing and changing needs for support and information in the sensitive area of pregnancy loss. We need to be equally responsive to changing financial climates, continuing to develop a more sustainable income base from a mix of fundraising, donated and earned income and ensuring that we have sufficient reserves to enable us to cope with the uncertain funding futures faced by many charities. This is the way to secure the future of The Miscarriage Association for as long as it is needed.

...and thanking our supporters

The Miscarriage Association would like to express our thanks to all those who have contributed to our funds this year. Grants, sponsorship, individual donations or the proceeds of fundraising events – every contribution, large and small, is greatly appreciated. While we are unable to list all our donors here, we would like to express special thanks to the following supporters who helped us maintain and develop our services in 2006 – 2007:

Statutory funding

The Department of Health

Individuals and groups

Babyloss

J & R Birtwhistle

Andrew Bunn & friends

Stacey Haynes

Morag & Kenny Kinghorn

Amanda Osgood

The Marshall family & friends

Kellie Matthews

Our London Marathon team

Charitable trusts & companies

D'Oyly Carte Charitable Trust

GlaxoSmithKline plc

IPC Media: *Practical Parenting*

JAH Norman Trust

Lloyds TSB Foundation for England & Wales

Marsh Christian Trust

Gifts in kind

Activ Computer Services, for e-mail and website hosting

Marks & Spencer plc, for providing facilities for Trustee meetings

RAP Spiderweb, for support in design and print



Kellie Matthews who completed the Women's HydroActive Challenge

making a difference: 2006–2007

The Miscarriage Association would like to thank all those who have been involved in providing our services during the year.

We are deeply grateful to our volunteer telephone contacts and support group organisers and helpers. Women and men with personal experience of pregnancy loss, they are the backbone of The Miscarriage Association, providing a national network of comfort and support to others in a similar situation.

Our thanks also go to those who help to recruit, train and support volunteers; our media volunteers; those who review books for the newsletter; and those who help us raise funds.

Our advisors and other volunteers who provide specialist advice and help are also indispensable. They have helped us answer medical queries, develop electronic communications, update our leaflets and plan for the future. Their contribution is strengthened by the support and commitment of the Trustees and our staff team.

We would like to express particular gratitude to the following people for generously sharing their time and skills:

- the members of our Professional Advisory Board
- the speakers and helpers at our conferences
- our patrons
- Peta Harrison, editor of our members' newsletter
- Nigel Wood, our webmaster



M.A. advisors Professor James Walker and Dr Christopher Everett

Patrons:

Tania Bryer
Nigel Martyn
Anna Raeburn

Professional advisors:

Ms Anne Jackson-Baker
Dr Christopher Everett
Mr Roy Farquharson
Ms Diana Hamilton-Fairley
Dr Sheila Kitzinger
Dr Marjory MacLean
Ms Christine Moulder
Prof Lesley Regan
Mr Naren Samtaney
Prof Gordon Stirrat
Prof James Walker

Trustees:

at 31 March 2007

Barbara Hepworth-Jones *Chair*
Alison de Verteuil *Vice-chair*
Caroline Williams-Racz *Vice-chair*
Penny Kerry
Sheila McPherson
Anne Walton
Peter Wright

Ex-officio:

Morag Kinghorn *Co-ordinator for Scotland*

Staff:

Ruth Bender Atik
National Director

Lisa Bruce
Senior Support Worker

Anne Woodhouse
Senior Support Worker

Andrea Allen
Volunteers Manager



Conference speaker Dr Caroline Gannon, Consultant Paediatric Pathologist



M.A. staff training session



Support volunteer Dawn Campbell

planning for the future: 2007–2008

The Miscarriage Association is a small organisation with a very big mission: to ensure that everyone who experiences the loss of a baby in pregnancy receives the support, information and care which she or he needs.

We will continue to offer a sensitive and knowledgeable support and information service for anyone affected by miscarriage, ectopic or molar pregnancy. We will work to make our services as accessible as possible, making the best possible use both of new technologies and of more traditional modes: our leaflets, telephone helpline and volunteer support network. We will continue to work with health professionals to support them in providing good and sensitive care for those who experience pregnancy loss. We will maintain our links with government and with professional organisations to ensure that the patient perspective is taken into account in developing policies and guidelines. We are equally determined to raise the public profile of pregnancy loss rather than allowing it to remain such a hidden grief.

Despite advances in medical research and treatment, miscarriage is still likely to affect hundreds of thousands of women and their partners in the foreseeable future. We want to ensure that The Miscarriage Association continues to be responsive to their changing needs and expectations, maintaining and developing accessible, high quality services that make a positive difference.

our plans...

- maintain our high-quality helpline five days a week, backed by a network of trained volunteers
- publish and promote a new leaflet for people with learning disabilities and another for deaf people whose first language is British Sign Language
- research and report on the need for information and support materials in additional languages and formats
- produce a leaflet for people who are facing a future without children after experiencing pregnancy loss
- develop an audio version of our most widely-used leaflet, both on CD and downloadable from our website
- work with the Royal College of Nursing and other key stakeholders to run study days on the disposal of fetal remains, and to revise national guidelines
- continue working with all the relevant professional organisations, government departments, hospitals and charities to improve care for couples who experience pregnancy loss
- work collaboratively with other charities to raise awareness of pregnancy and baby loss
- maintain our reputation as an expert source of information on the facts and feelings of pregnancy loss

...and how you can help

- become a member of The Miscarriage Association
- join our UK-wide volunteer network
- talk to family, friends and colleagues about our work
- become a Friend of The M.A. with a regular monthly or annual donation
- encourage your employer to implement payroll giving and join in to enjoy tax relief on your donation
- persuade your employer to become a corporate supporter
- take part in one of our fundraising events – or organise your own
- sign a Gift Aid declaration and increase your donation at no cost to yourself

“ Losing my baby has been the most devastating and painful thing I have ever had to go through. In my deepest pain, desperation, confusion and loss, The Miscarriage Association enabled me to keep breathing.

I want to thank everyone in this organisation, especially those I spoke to on the phone.

I truly know that without you, I would not have made it this far. ”