NARA - Annual Charity Report

FOR FINANICIAL YEAR ENDING 30th APRIL 2019

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Registered Charity 327033

NARA Annual Report - 1st May 2018 to 30th April 2019

End of an Era

Since its inception in 1983, our charity has had a stalwart piece of equipment available to parents and carers to see them through particularly anxious and difficult periods when their tiny baby stops breathing. The ultimate medical device to go to has been the Graseby MR10 Respiration Monitor. First developed in the late 1970s by a team of specialists, notably including Dr Martin Wright of the Bioengineering Division of the Clinical Research Centre, the MR10 initially produced by Pye Dynamics (later to become Graseby Medical, then Smiths Medical) monitored breathing in infants in a new and pioneering way. Together with Professor John Scopes at Hammersmith Hospital, the pair had been looking into observing infant respiration following a number of unexplained deaths. Their ultimate goal was to develop a device that would alarm should the baby stop breathing, so the first objective was to design a sensor.

Pye Dynamics MR10
Photo credit BMJ Archive

The most breathing movement was found to be on the lower abdomen of the baby, rather than the upper, or chest area. A number of trials took place including a sensitive mattress and a belt, but both had flaws some

were considered clumsy and others impractical for everyday use. This design work was now centred at Northwick Park Hospital in London, and now another expert in the field, Mr Kevin Callam, had joined the project too. Finally, a small plastic pneumatic sensor was devised, which was taped to the abdomen of baby, the changes of air pressure in this sensor was transmitted via a tube to a small box of electronics that converted the changes of pressure into electronic signals and giving a gentle audible ticking noise and a reassuring flashing green light when things were stable and in order. Should there be no change in the air pressure for a brief period of time (10 or 20 seconds) an alarm would be set off; a high pitched, shrill, audible alarm together with a bright flashing red light. This alarm would summon urgent assistance. Following an intense and extensive period of testing the device proved to be both acceptable, reliable and easy use for nursing staff and, what's more, the previous worrying infant mortality rate, which spurred this whole initiative, had been significantly reduced in Northwick Park Hospital - indeed, unexplained mortality was completely eradicated.

Dr Martin Wright
Photo credit BMJ Archive

Dr Martin Wright and his team went a step further in hospital conditions where the respiration monitor was attached to a ventilator, so once a nil response was detected the alarm would not only summon help, but also trigger the ventilator to kick in to assist the ailing infant - this development, however, was not something that could be used in a domestic, or home environment.

The device was, in electronics terms, very simple in design and the components were cheap and therefore ideal for mass production. Essentially, Dr. Wright and his team were true innovators of an efficient respiration monitoring device that not only was to become the mainstream device in Special Care Baby Units and Paediatric Wards, but could be used in the home - obviously the latter would include an element of training, especially in infant resuscitation. It was a world leader.

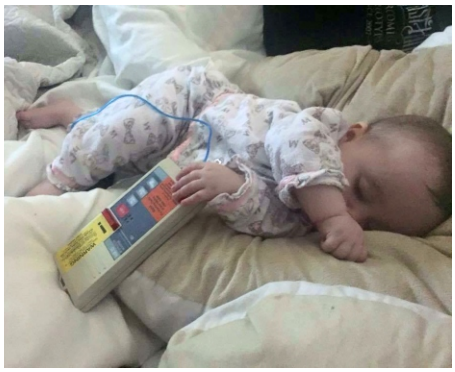
In 1983, the founding families of NARA, were introduced to the MR10 to assist their own children, one who suffered unexplained apnoea episodes, the other a sibling of two previous cot-deaths, both were completely successful. NARA was born out of the need for these tried and tested respiration monitors to be available in the home for parents of babies who were considered at risk of 'cot death', or who had significant respiratory issues. Unfortunately, despite the successes at Northwick Park Hospital, home use of these alarms was not something that was universally accepted by many paediatric hospitals or other medical organisations specialising in unexplained infant mortality.

Although just a small charity, NARA became an advocate of home monitoring promoting and providing equipment for anxious parents across the UK when funds allowed. Over the next 30 years, the MR10 went through a series of updates and upgrades, these were more ergonomic rather than changing the original basic operational systems, which remained constant. Also, over these 30years, there were many devices appearing on the market that tried to duplicate the MR10, however, during that time, and even until today, the device has never been duplicated. Unfortunately, in 2013, a decision was taken by Smiths Medical to cease production of the MR10, in June 2018 this also precluded servicing and repair to existing machines in the field due to the unavailability of spare parts. It was a truly sad day, which ultimately saw the death knell of a device that NARA had used throughout its entire history with immense success relieving anxiety for many thousands of parents, providing that all important alarm to summon assistance when baby stopped breathing and ultimately saving a good number of tiny lives.

As we've previously stated, the MR10 has been often imitated but never duplicated, we trust the day the MR10 is emulated is not too far from the horizon. As our last report states, NARA are currently trialling a new more sophisticated piece of equipment, the PulseGuard alongside the MR10, aimed at babies and children suffering apnoea due to more complex conditions, and to date have had very good results. We have

Incarnations of the MR10

1980s -1990s



1990s - 2000s

2000s - 2010s

found this equipment to be an absolute necessity for babies, children and adult with the more complex conditions. We have also trialled a smaller apnoea alarm that fits on the baby's nappy, the Snuza Hero, with a fair result, but find although suitable for stable use (i.e. in a cot) they are not portable enough for NARA's end result. The whole ethos of what we do at NARA is aimed at portability to enable those who can the ability to escape their four walls, giving them a better quality and far more enjoyable way of life. We continue to search for a replacement, it has become a core priority for us - watch this space for further news.

How the MR10 has helped

These few stories show just how important this equipment is and why there is the need of a replacement.

Updates on 'Our Little Boy' - Jonah

Update 2014 *- Our little boy, Jonah, is now 3yrs old and unfortunately still stops breathing, he has an apnoea monitor, so his parents can give him any assistance he needs when he stops breathing. He has recently been diagnosed with Chiari malformation, which is a malformation of the brain. It can cause headaches, fatigue, muscle weakness in the head and face, Sleep Apnoea, Sleep disorders, dysphasia (difficulty swallowing), dizziness, nausea, impaired coordination. For full details of Chairi see drop down menu on 'what we do' at www.naratbc.org.uk. Thank you for looking.*

Jonah playing Michael Darling in Peter Pan
Photo credit St Helens Theatre Royal

Update 2019 *- Our precious boy is now 8years old. He's come on so much and overcome so much. We are so grateful to NARA (Ann Jiggle) for helping us when no one else could. We only need his monitors when he is poorly now. When he is well, he's able to wake himself when he has apnoea now. However, Jonah still struggles everyday with his condition, but it never stops him enjoying life. He is an inspiration to everyone who meets him, and we are so proud of everything he has achieved so far.*

Kaitlin's Story

Most of you know that approximately this time 6years ago our beautiful Kaitlin suffered a cardiorespiratory arrest. It was a horrific time. Following resuscitation by the amazing A&E team at SGH (hospital) she spent several days in a coma under the watchful care of the fantastic PICU team. When moved to a general ward we watched and waited for her recovery, to see any impact of such a significant event. When ready to be released home to us SGH wanted both Kaitlin and Erin to go home with breathing monitors to alert us should anything reoccur and try to put our minds at ease. Sadly, all monitors from hospital sources were in use and we underwent lots of discussions with the doctors plus additional life-saving training from the ambulance unit but we were still advised that until we had what we needed we weren't to be discharged. I wracked my brains and began scouring the Internet, to buy monitors but the cost of 2 was unaffordable. Then I came across a charity called NARA. I called and spoke to the most wonderful lady. She was reassuring and kind. Within 24 hours we had 2 monitors with equipment couriered to the hospital on loan for as long as we wanted or needed them!! We were overjoyed and able to return home and reunite our family after several weeks as inpatients. The girls wore their

Above: Kaitlin and her twin sister, Erin, aged one year with Ann
Below: Kaitlin today

monitors until they were one and on their first birthday I remember having the absolute privilege of meeting the voice at the end of the phone who gave me comfort and brought our family back together, lending us life-saving equipment when we needed it most. Parents in the situation we were in or worse are out there, needing help, needing equipment, the NHS is pushed financially to it limits and charities such as NARA are becoming vital.

A Mother's Story

Joshua as a baby ….

Joshua was born with Beckwith-Wiedemann syndrome (BWS), a rare condition that only affect 1 in 15,000 babies. He spent a total of 6 weeks in the hospital NICU. As a result of his syndrome Josh has a long list of complications, one of which is Sleep Apnoea. If it wasn't for NARA providing us with equipment that monitors Josh's breathing through the night, during naps and car journeys we wouldn't have been able to keep Josh safe at home. His monitors have alerted us a few times during the night where we have had to wake Josh to ensure he is breathing and safe. We can't thank Ann and NARA enough for helping us keeping our little boy safe. Thank you all so much for everything you do.

On behalf of all Trustees, staff and parents helped over the last 35years, NARA would like to take this opportunity of thanking the innovators of the MR10, Dr Martin Wright and his team together with all staff involved in supplying and servicing the MR10 respiration monitors at Graseby and Smiths Medical initially at Watford and more recently at Luton.

Nebulisers

We turn to our nebuliser patients now, which involves our work with those who suffer severe respiratory conditions that requires medical intervention and the administering of medication via a nebuliser. We have worked extensively with healthcare professionals nationwide in relation to this for a good number of years. Some of them wished to let supporters of NARA know how appreciative they are of the service given.

South Tees Area Health Authority

I would like to express my thanks for the equipment of nebulisers that the charity has provided to respiratory patients in the South Tees area. Although I am no longer in post as a community matron, I can confirm that several patients benefited from the equipment you supplied. This varied from patients with bronchiectasis, asthma COPD and lung cancer. This helped prevent hospital admission and improve quality of life. I have always found the charity very helpful, in particular Natalie who have spoken to several times. I am aware you are a small charity but the donations of individual nebulisers you supplied enabled us to re-loan out some of our emergency stock. I hope to continue to work with you in the future in my new role.

Thank you so much,
Rosie

Rosie Watts, Nurse Practitioner, The Garth Surgery, Rectory Lane, Guisborough

Community Respiratory Team for Cambridge

I would like to forward my sincere gratitude for the support and assistance the team at NARA provide to our team and our patients. The service they offer is excellent and it makes a significant difference to our patients quality of care we are able to provide. Our patients frequently feedback regarding how lovely and supportive they are. The patients feel the team is approachable and

… and Joshua today

The Garth Surgery, Guisborough

100 year old Gwendeline Cambridgeshire

informative. As a team the ladies at NARA always communicate well with the team and inform us if there any concerns. This service is wonderful, and several patients have commented "what would we do without them".

Kind regards,
Jess.

Jessica Rowland, RN, MSc, Non-Medical Prescriber, Specialist Practitioner - District Nursing Band 6 Nurse, Community Respiratory Nurse, Community Respiratory Team for Cambridge.

James Paget University Hospitals NHS Foundation Trust

I wish to express my team's thanks for your Charity NARA's continued support to supply our Head & Neck Oncology and Neck-Breathing patients with long term loan of nebuliser equipment. Without this continued support and added resource we would struggle to provide a continuous loan of this specialised equipment to meet our patient's needs. Many thanks again from a grateful hospital-based nursing team.

Regards
Vanessa

Vanessa Wakeford, Head & Neck Sister, James Paget University Hospitals NHS Foundation Trust Lowestoft Road, Gorleston, Norfolk.

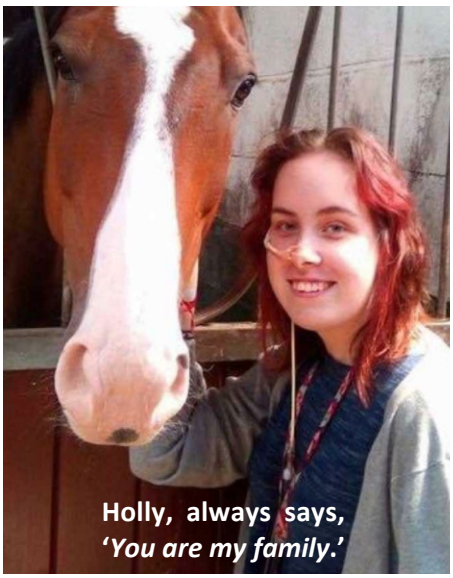
Working closely with GP surgeries, healthcare professionals, specialist respiratory departments and other related departments helps us as a charity to get the most appropriate care and assistance to our patients. In many cases, where we have a stock available, patients can be given medical equipment direct from their doctor, or surgery, rather than needing to wait for long periods of time for us to give help. Of course, especially in the winter months, where infections and viruses are most prevalent then a slight delay may occur, but, in the main, we like to think we have the correct equipment, for any patient requesting, installed within an average of 7-10 days of them applying.

Of course, in the main, patients needing our assistance contact us direct and we deal with them on an individual basis. Although these individual cases are more personal, we do engage with healthcare agencies so that our patients are offered the maximum support in relation to their conditions. Ultimately, our charity's ethos is to offer those with severe respiratory conditions a better quality of life. To many that may be just an opportunity of escaping their own four walls to go to the shops for an hour a day, something that most of us wouldn't even consider as much of a big deal. To someone with life limiting conditions it does much to lift their spirit and make them feel they are part of their own community.

Over recent years, another use for nebulisers has been in a patient's last days. A time when they wish to spend time to be with close family and friends giving them an opportunity of bidding a final farewell. Palliative care is so important, not only for those who are approaching their final curtain, but for loved ones to exchange those important last words, put previous records straight and offer those messages of love and warmth that may have been missed. All this done, not necessarily in a hospital or similar environment, but in their house – the place they call home, and on their own terms you may say. The medical equipment provided by NARA can offer them that final freedom, may be just for a few weeks, or a handful of days. We're often told by surviving relatives, that patients who are able to do this feel it's their last act of defiance against a condition that has blighted their loved ones' lives.

Over the past financial year NARA has provided 35 respiration monitors, 138 nebulisers and 60 other pieces of medical equipment into the community. We have responded to 1117 telephone enquiries and have visited 125 patients ensuring they are well, and their equipment is in good working order and remains appropriate for their condition. During this period too, we have responsibilities for 670 current patients. Through many sources we have been able to support and care for our patients almost 24hrs per day, 365 days a year, including social media (over 1000hrs of support on social media), to be there on those occasions when a friendly word, or simply just to talk offering encouragement, or in those difficult times when they are feeling particularly low, even in times of despair. With their explicit consent and approval, we also direct patients to other organisations where extra, or more specific help is required beyond our remit.

We have a good number of young adults who, because of their illnesses, have difficulty engaging with their

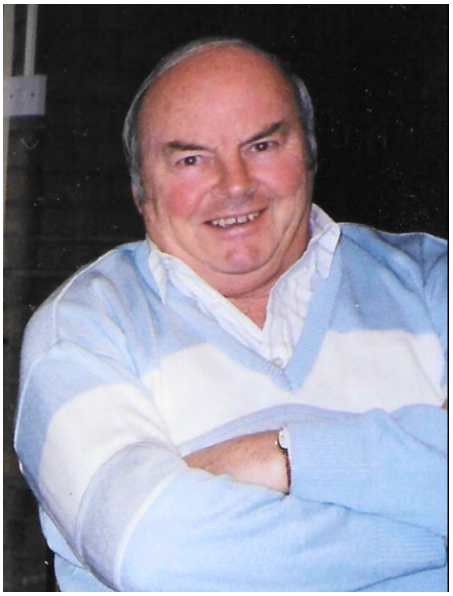

Holly, always says, *'You are my family.'*

piers or not feeling part of their age group. They can believe they're excluded and isolated from the here and now when life memories are made. Some become very frightened of everyday life and equally of what the future holds – even death. However, it's amazing what a casual chat, or the odd bunch of flowers or small gift can do to lift spirits, reassuring them someone is there and cares for them. In fact, one of our patients, Holly, always says, '*You are my family*.'

Accounts

Looking at the accounts, we are around £5,500 up on the total of the previous year, with direct medical expenditure increasing by a little over £3,000 as a result. Fundraising and administration costs are an area of expense that have risen slightly as a project for the next financial year gets underway, much preparatory work and organisation is necessary to achieve a good outcome, which should bear fruit next year. On the whole, with the significant national downturn in business, trade and other financial indicators due to Brexit and other political reasons, we were so pleased to have an income commensurate with the past few years to continue our work with those who suffer with severe respiratory conditions. Thanks for this has to be bestowed upon the countless individuals, groups, companies and organisations that support us year on year, many of which who wish to remain anonymous. Nevertheless, there are a handful we'd like to specifically thank, these include NEXT, The Shire Bears, Lothian Buses, Edinburgh - who have taken us under their wing for several years now, RS Components, Corby, who we've built up a great rapport with, together with two organisations, The Toy Trust and The Persula Foundation who have donated grants to us quite regularly. Our income this year was also augmented by another legacy, only the second we have received, but an absolute godsend. Financially speaking, we trust that the next accounting year is just as good, but with so many variables only time will tell.

Mr Fred Whiting



We end on a very heart-breaking note having to report the sad loss of our dear Trustee, Mr Fred Whiting, who died suddenly on 11th April 2019. Fred and his wife, Iris, were keen supporters and Trustees of NARA who would offer any help they could. When Iris died, some 20years ago, we thought Fred may draw away from his responsibility as a Trustee, but no, not him. He continued to put 100% into the job at hand as he'd done previously, effectively with even more vim and vigour than before. He was always there as a guiding mind, helper and advocate of NARA and all the charity stood for. Obviously, he will be sorely missed not only as a person, but his positive and upbeat personality with his quick 'off the wall' sayings, his 'matter of fact' approach to life and the way he encouraged others will certainly make things difficult in these still raw days of his passing. The charity will be the poorer in spirit following his loss. We would all like to take this opportunity of thanking Fred for his loyalty and devotion to duty and trust he can 'Rest in Peace'.

Finally

We leave this year's report with a poem penned by the mother of one of our patients, Hope. Hope is a young lady who battles to breathe on a daily basis. Her Mum's words eloquently express Hope's daily fight to simply breathe:-

Breathe in, breathe out

Breathe in, breathe out, it's as easy as can be,
But I listened and thought, ' hey, this is not for me.'
My lungs are heavy and need a rest,
it feels like an elephant sat on my chest,
I want to dance, jump and run,
but my illness is saying you're not having fun!
You need to breathe you silly thing,
but whilst I'm not working I shan't let you sing.
So, breathe in and out as deeply as can be,
It should be simple, but not for me.
But each day, 'I'll try as hard as can be, to breathe in and breathe out,
my illness won't beat me!'

NARA - Annual Charity Accounts

FOR FINANICIAL YEAR ENDING 30th APRIL 2019

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Registered Charity 327033

Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle F Whiting E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Andrew Nottingham Taxwright 65 Moss Street Keith Banffshire AB55 5HE
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

I report on the accounts of the Trust for the year ended 30 April 2019 which are set out on pages 3 and 6

Respective Responsibilities of Trustees and Examiner

As the charity's trustees you are responsible for the preparation of the accounts: you consider that the audit requirement of Section 43(2) of the Charities Act 1993 (the Act) does not apply. It is my responsibility to state, on the basis of procedures specified in the General Directions given by the Charity Commissioners under Section 43(7)(b) of the Act, whether particular matters have come to my attention.

Basis of Independent Examiner's Report

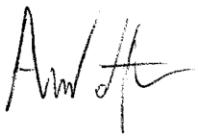
My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given by the accounts.

Independent Examiner's Statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements
- to keep accounting records in accordance with section 41 of the Act: and
- to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the Act have not been met or

(2) to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



A W Nottingham FCCA
Taxwright
65 Moss Street
Keith
Banffshire
AB55 5HE

Date 27/1/20

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Statement of Financial Activities
For the Year Ended 30 April 2019

	Notes	Unrestricted Funds 2019	2018
Incoming Resources			
Donations from Grants, Trusts, Companies and Individuals	2	116,021	110,743
Direct Charitable Expenditure			
Medical equipment care and support		96,266	93,429
Other Expenditure			
Fundraising costs		4,384	3,211
Management and Administration of the Charity	3	15,330	12,778
Total Expenditure		115,980	109,418
Loss in value of monitors		5,000	-
Expenditure after exceptional cost		120,980	109,418
Net Movement in Funds for the Year		(4,959)	1,325
Total Funds Brought Forward		40,608	39,283
Total Funds Carried Forward		35,649	40,608

There were no recognised gains or losses for 2019 other than those included in the Statement of Financial Activities.

The notes on pages 9 and 10 form part of these accounts.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2019

	Notes	2019	2018
		£	£
Fixed Assets		33,344	38,344
Current Assets			
Cash at Bank and In Hand		2,773	2,756
Current Liabilities	5	(468)	(492)
Total Assets less Current Liabilities		35,649	40,608
Capital			
Unrestricted Funds		35,649	40,608

Approved by the trustees on 25th February 2020 and signed on their behalf

Trustee

The notes on pages 9 and 10 form part of these accounts.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts

For the Year Ended 30 April 2019

1 Accounting Policies

1.1 Basis of Preparation of Accounts

The accounts are prepared under the historical cost convention and include the results of the charity's operations which are described in the Trustees' Report and all of which are continuing.

The accounts have been prepared in accordance with the Statement of Recommended Practice for charity accounts.

The charity has taken advantage of the exemption in Financial Reporting Standard No 1 from the requirement to produce a cashflow statement on the grounds that it qualifies as a small charity.

1.2 Income

Voluntary income and donations are accounted for as received by the charity. The income from fundraising ventures is included gross, with the associated costs included in fundraising costs. No permanent endowments have been received in the period.

1.3 Value Added Tax

Value Added Tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

1.4 Fundraising Costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

1.5 Management and Administration Expenditure

Expenditure on management and administration of the charity includes all expenditure not directly related to the charitable activity or fundraising ventures. This includes costs of renting and running office premises, staff salaries for administrative staff and fees of an independent examination.

2. Income

	2019	2018
	£	£
Donations	115,041	109,538
Medical Contributions	980	1,205
	116,021	110,743

3. Administration Expenditure

	2019	2018
	£	£
Office Rent and Services	6,431	6,369
Administration Staff	8,431	5,917
Independent Examination	468	492
	15,330	12,778

4. Staff Costs

No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	2019	2018
	£	£
Wages and Salaries	8,431	5,917

The average weekly number of staff employed by the charity during the year was as follows:

	2019	2018
Administrative	1	1

5. Current Liabilities

	2019	2018
	£	£
Accrual	468	492