



FINANCIAL YEAR ENDING 30th APRIL 2024

NARA - *Annual Charity Report*

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NARA Annual Report - 1st May 2023 to 30th April 2024

From a Little Acorn ...



It's difficult to believe and quite humbling, in equal measure, to understand that our charity was founded some 40 years ago, in 1984. Difficult in wondering where those 40 years have gone, time certainly moves very fast; humbling to believe the British public have supported our cause for so long, not only with their donations, but their encouragement too.



Kary and Iain with their respiration monitors

NARA was founded following the plight of two Northampton babies who suffered apnoea episodes, which means they kept stopping breathing for no apparent reason.

Our story began on an early summer's day in June 1983, when the first baby, Kary, was just six weeks old when her parents found her blue in her carry cot. They panicked and probably did all the wrong things but got her breathing again.

Within the hour Kary had stopped breathing for a second time. Again, panic set in, but her anxious parent got her breathing. This time they took her straight to the doctor, but when they arrived in his surgery Kary was rosy cheeked, smiling and showing no signs of there being anything wrong. After relaying the apnoea incidents to the GP Kary's worried parents were dismissed as being neurotic and exaggerating the two incidents.

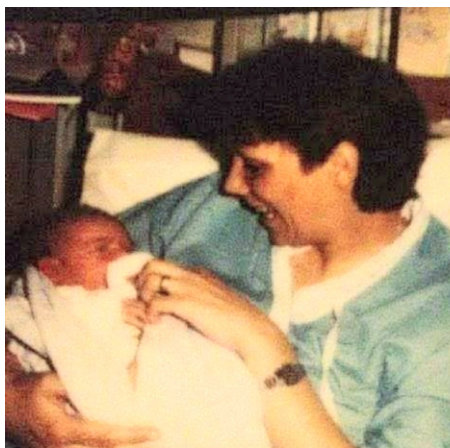
Back at home, life was very tense for Kary's parents as one of them was always looking over her to ensure she didn't stop breathing again - day and night. With two other children to look after, time was very tense. Thankfully a visiting health visitor

witnessed Kary having a further episode of not breathing, and at last her parents were taken seriously. Kary was admitted to Northampton General Hospital where various tests were carried out, unfortunately with no direct reason for the apnoea episodes, it appears she 'just forgot to breathe'.

Kary's parents were told to purchase a respiration monitor, which would alert them should she stop breathing again. It took a while for them to source a reliable product, but they did. It was truly a life saver, Kary had more apnoea episodes during her next two years, many times the alarm would sound, and she'd start breathing again, but on 15 occasions she had to be resuscitated. The monitor used was the Graseby MR10, a light, portable monitor, that uses a pneumatic sensor attached to the baby's tummy. This was preferred to the mattress monitors available, which only operated in a static position, like a baby's cot, not in a pram or carry cot in a car. Kary's parents had learned very early on, that cot deaths, or in their case, apnoea attacks, didn't just happen in cots, it could happen at any time and anywhere.



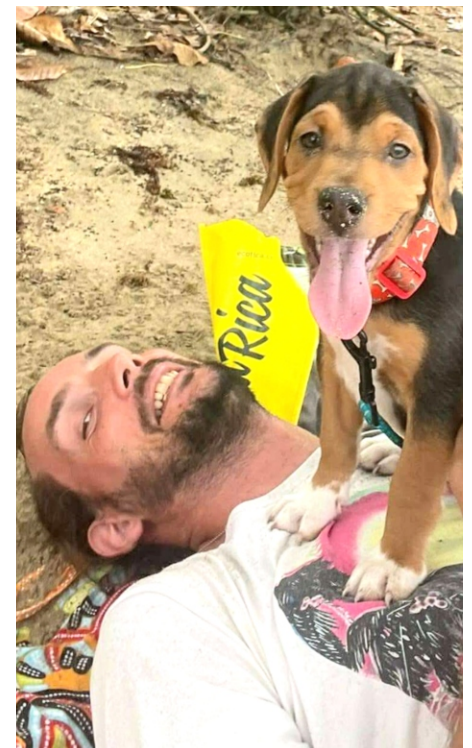
Kary at a few months old



Iain and his mum



Kary today - has a passion for motorsport



Iain today - is a chef in Costa Rica

The second baby was Iain, sadly his mother had had two cot deaths previously. In December 1983, Iain was admitted to Northampton General Hospital following him suffering similar apnoea episodes to Kary, again for no apparent reason. His mum was told to buy a respiration monitor, prior to him being released.

Family and friends of Iain's mother immediately knocked door to door around the area they lived trying to raise enough money to purchase a monitor. Living nearby, this is when Kary's parents and Iain's family and friends first met. The appeal for Iain's monitor was very successful, it not only raised enough



The 'original' MR10 monitor was £300

money for his monitor, but enough to buy more. At this time, respiration monitors cost £300, but another £100 was needed for disposable sensors.

1984 -1994

In early 1984, Kary's parents and Iain's mother united in their hope to raise further funds to purchase more monitors for similarly placed parents of children suffering apnoea.



Soon, enough money had been raised to purchase six monitors and six packs of sensors, with a surplus of money available to keep the monitors running for at least a year. The hope was to donate these monitors to Northampton General Hospital, not for hospital use, but for home use. Whilst in hospital, monitors were available, and 24/7 care by nursing staff supported these babies, but when they were home there was nothing. This meant parents would have to sit by their baby to ensure they continued to breathe normally. This is where the help was needed. Unfortunately, the hospital couldn't guarantee that the monitors could be used in this way, they'd be used for ward use in the main. That wasn't an option for the group, now called 'Help Prevent a Cot Death Appeal', who'd raised the funds, so they left the hospital with the monitors to consider their next move.

Not too long later, due to local press exposure of what we'd achieved, a local mother from Northampton contacted us, Christina, unfortunately she had suffered the loss of a child, a baby daughter called Sarah,



Christina and Adele in 1984 ...

through 'cot death'. Christina had just given birth to a baby daughter, Adele, and was very anxious that she may lose her too. She asked if we could provide her with a respiration monitor. Of course, we wanted to help, but we had to look closely at the logistics of doing just that. Before we could give any help. Firstly, we needed to contemplate the following questions; legally how do we stand loaning the equipment, how do we do this with the approval of medical staff responsible for the child, what support we would need to give both mother and child, and who would offer resuscitation advice.

We took advice from many bodies including solicitors, GPs, paediatricians, health visitors and the Red Cross, who were expert on resuscitation for both adults and children. We had particular help from Dr Peter Swift a leading paediatrician from University Hospital Leicester and much input from Graseby Medical the manufacturers of the respiration monitors. We managed to get enough information together to allow us to help Christina and her daughter Adele within days of her request. This was the very moment our appeal became fully operational.

We'd like to take you on a journey and look back over the past 40 years, recalling some of the key moments, and illustrate a number of patients we've helped and, like Adele, show where some of them are now. Also, to see how our initial local 'Help Prevent a Cot Death Appeal' developed into a national registered charity, nowadays helping others of all ages who suffer chronic respiratory issues.

It was during the summer of that year, via national tv and newspaper coverage, when we heard of the sudden passing of a baby girl, Elizabeth, in Somerset. She was a sibling of IVF triplets. Our situation was that we had a number of respiration monitors on a shelf doing nothing. We therefore contacted the hospital to ask if the surviving siblings, Jennifer and Robert, would benefit from the use of a monitor each, especially after being discharged. We were told by their



... today, they both live in Australia

paediatrician they would. So, we set off to Somerset to deliver the monitors, explaining fully how they worked and insisting the parents were given resuscitation training. A few days later the babies were discharged. The story of these triplets had caught the imagination of the national press, and a number of newspapers sent staff to cover the baby's leaving hospital.

A curious journalist asked what the little 'ticking' boxes were. They were told about the respiration monitors by the parents, who also told journalist to contact us in Northampton to find out more about our appeal.



We found the publicity to be a double-edged sword

The publicity of this one event significantly boosted awareness, but we found it to be a double-edged sword as more people wanted help than we could possibly deal with. However, a number of other events saw us gain financially too. We were contacted by a programme researcher of the then popular tv series 'Bullseye', courtesy of a contact with one of the stars, Tony Green, who was the scorer, and worked closely with the main presenter, Jim Bowen. The 'Bullseye Christmas Special' was to support charities, rather than members of the public. In the programme, the scorer Tony Green, became the dart thrower, and Ann Aston, who'd previously worked on another successful tv show, 'The Golden Shot', would calculate his score. Ann played her part on the show by giving the appearance of struggling with simple arithmetic when



Jim Bowen and Tony Green of tv's Bullseye fame

calculating contestants' scores. In the Bullseye Christmas Special, Tony Green failed to score maximum points for us, but Ann's spurious adding up allowed us to be given the maximum £300. Jim died in 2018, and we learned that Tony sadly passed away during this year - he was a great support to us in the early days of our charity.

From there, public interest in our work grabbed the attention of producers of BBC's weekday 'Pebble Mill at One' lunchtime show.



A few days after we'd been featured, we had a phone call at around 2am in the morning, surprisingly from the former British and European featherweight boxing champion, Barry McGuigan. His then baby daughter,



Grateful for our help, Barry McGuigan, MBE, helped raise money for a number of projects



Filming of the Five A Day video

Danika, who was just a few weeks old, had suffered apnoea attacks and he was beside himself with anxiety, not knowing what to do. After talking with doctors caring for Danika, they agreed both she and her parents would benefit by the use of a respiration monitor. Barry was so thankful for our help, he paved the way for a number of fundraising projects, firstly to fund further monitors, by organising an amateur boxing evening at the Cafe Royal in London, which raised enough money to buy 30 monitors - at that time, our biggest fundraising event by far.

He later helped fund an educational video showing parents when and how to resuscitate their baby. It was called 'Five A Day', as during the 1980s that's how many babies died of 'cot-death'. This was done in collaboration with the Royal Society of Medicine, and was the first video of its kind in the U.K. - it also won an award from the British Medical Association.

By early 1986, we had completed the necessary paperwork and legalities to be already formally registered with the Charity Commission, with a full title of the National Association for the Relief of Apnoea (NARA). In mid-1987, just three years after we loaned our first respiration monitor, thanks to the generosity of the public, we had helped 300 babies, their parents and/or carers with respiration monitors. To celebrate this, and more importantly, to get these babies and their parents together, and, of course, to continue the stream of positive publicity we held a party. This was held at the Cafe Royal, London, and again kindly supported by them. The event attracted a good number of families we'd helped, and a number of then celebrities. It was a really special day, giving us a chance not only to meet and greet these families, who'd been through a trying time, but to thank some others who'd been instrumental in helping us with the support



The NARA party at the Cafe Royal, London, was a great success Parents were able to engage with other parents whose babies had breathing problems

STARS KO'D BY SUPERKIDS

LUCKY-to-behave soccer, including a number from Northampton, celebrated in style at the weekend with a massive party at the Cafe Royal, London.

For all the 300 babies, a special celebration was held in the country and the party was held at the Cafe Royal, London.

Now that 2000 babies do not suffer from asthma, the party was held in the country and the party was held at the Cafe Royal, London.

The local newspaper gave thanks to the various celebs, who were amazed to be invited and hear their stories

David Amess MP attended with his wife



• Above: Two-year-old Sam Deabornough, of Northampton, who is said to be from Blue Peter star Janet Elie.

• Right: Radio 1 DJ Justin Long chats to Angelique (1) and Simon Callard (4) from Mersey, Northampton.

• Top left: 'This' TV star Bill Buckley with Tamara Sheppard (11) mother of Louisa.

• Left: Christopher Lillibridge, children's TV presenter, with Mark Dennis (12 months, from Weston Favell).



• Above: Meeting Geoffrey Frost (Northampton) in the main, was dealt with by the use of inhalers, sometimes referred to as puffers.



David Amess MP attended with his wife

The local newspaper gave thanks to the various celebs, who were amazed to be invited and hear their stories

and advice to help us get our now, national charity, up and running. Special thanks here must be given to the late Conservative MP for Southend, Sir David Amess, who was not only a font of knowledge, but continued as a significant fundraiser for us for a number of years after.

Thanks to a number of then celebrities attending, a pantomime performance given by an amateur dramatic society, and a magician adding entertainment, the children, their mums, dads, brother, sisters and carers, a true party atmosphere was generated. Parents, who once seemed isolated with their baby suffering near death experiences, were now socialising with others who'd been in a similar situation. This was valued by many; their feeling of remoteness had been banished in one afternoon. Yes, the Cafe Royal party was a fantastic and very worthwhile event.

We had had some great success providing monitors and support to parents, these were highlighted at the Cafe Royal party, indeed, many of those helped wrote to us, post event, with similar words to those sent to us by a mother, Alison, from Bedfordshire, after we'd given her a monitor for her baby daughter, Florence. In her letter she wrote, *'I would like to thank you very much for the use of the alarm, which has given me a great peace of mind in those vital early months and also thank you for your kind attention. I must also add that our children very much enjoyed the party in London and my eldest daughter still talks about it. It must have involved a great deal of work and thought and was well worth the effort.'*

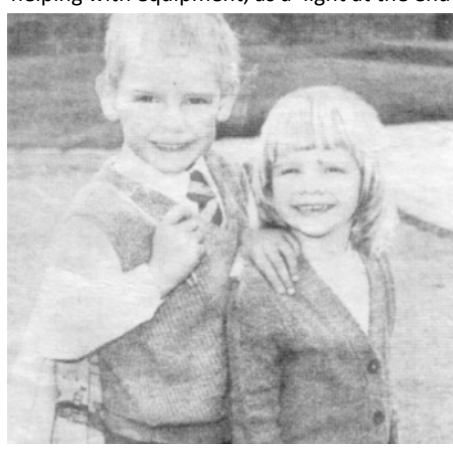
Looking back, it is a shame that we've not been able to repeat this event, but, to date, the opportunity to do so has never arisen - one day, maybe?

However, we did have some tragic stories too, including a 16-year-old unmarried mother, from Northamptonshire, whose baby suffered a traumatic birth. Baby Christopher

was severely brain damaged, and his mum requested a monitor, which we gave. After a few short weeks, the very brave mother said that Christopher had suffered a number of seizures, each one made his condition much worse. She wanted to give the monitor back, it had helped her 'get to know him', but she didn't want to intervene and resuscitate her baby son should it happen again. A few days later Christopher sadly died, but what a brave decision, by such a young mother.

Also, we helped a baby boy, Luke, who suffered apnoea attacks and had not had any episodes for a number of months. Luke's mother felt confident that he was finished with it. A few months later we learned that Luke's dad had been killed in a car crash. If that wasn't bad enough, just another few months later the family home caught fire during the night - all perished, except for the mother. There are no words to aptly describe her loss, nor her absolute despair.

On a brighter note, 1988 was an important year for both Kary and Iain, who were now, preparing to begin their first day at school. This seemingly simple event was considered by the parents of 'new' babies we were helping with equipment, as a 'light at the end



Iain and Kary started school in 1988. It was a significant time for them both

of a tunnel' sign - if these two children, who were poorly at a very young age, could survive, then their child could do the same.

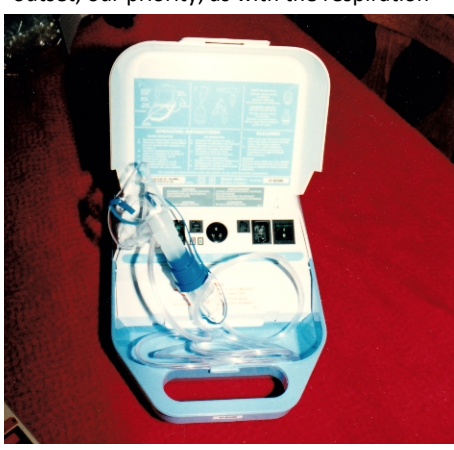
During the early 1990s, due to a serious illness to one of the Trustees, the charity, whilst continuing to operate, trod water for a couple of years, keeping a relatively low profile, but still offering help and support when needed. This was possibly one of the lowest ebbs we'd suffered, before, or since.

However, during this period, our positive relationship with medical professionals highlighted a serious need, not only with children, but with adults of all ages too. Hospitals and surgeries seemed to be suffering a serious influx of patients suffering from asthma. This condition, in the main, was dealt with by the use of inhalers, sometimes referred to as puffers. Medication was delivered through these devices when a patient felt an attack coming on. Nevertheless, whilst a good number of patients could be dealt with in this manner, at this time, there seemed to be a significant spike in the number of patients suffering more serious respiratory conditions. We were therefore asked if we could step in to assist patients by providing them with nebulisers - machines that atomized medication into a fine mist that could be forcibly inhaled and absorbed to effect relief, for those gasping for breath and restoring them to relatively normal respiration.

Taking on board this new need, firstly, we had to check our charity constitution to see if we could entertain taking on such a request. Looking at the relevant paragraph that dealt with our remit, it reads :-

'The objects of the National Association shall be to relieve sickness by the provision of respiration monitors or other medical equipment to infants whose lives without such equipment would otherwise be at risk, and by the supply of general medical equipment to such infants and other persons who are sick, convalescent, disabled, or handicapped.'

Other persons who are sick, etc, gave us the ability to help people of all ages. So, finding we could, our next move was to look at the various nebulisers on the market and understand how they worked and the conditions they aimed to assist. From the outset, our priority, as with the respiration



The World Traveller nebuliser offered a new freedom for asthmatics

monitors, was the portability of such devices. Our aim wasn't just to provide this necessary medical equipment, but to improve the quality of life for those requiring such equipment. Many of these patients suffering from these acute conditions were confined to their house, not only because of their illness, but also needing to be around electricity connections to power the nebuliser.

Our research found the best equipment to use was a World Traveller, made quite locally to Northampton by a company called Medix, this was a great help as we could call into their works for advice and repair, should it become necessary. By definition, we found this machine to do exactly what we wanted. It could be powered by mains connection at home, ironically, by plugging into a cigarette lighter in a car, or by its own rechargeable internal power pack. So, it was truly portable, it could be used in the UK, or in Europe as it had flexible voltage input. The compressor was strong enough to deal with the thickest of medications through the nebuliser itself. There was just one drawback, it was quite heavy to carry, although, after using it for a long period of time, we found only those who were very elderly and quite frail, or those suffering from brittle asthma, were affected - these patients were minimal in comparison to those who benefited from the equipment. Another asset in using these machines was that they could be easily maintained, and sterilised, by qualified repairers, should they break down, allaying the fear of any cross contamination too.

One of the first nebuliser patients was an elderly lady who lived on the outskirts of Manchester, just off the M62. She had suffered for many years with COPD, or chronic obstructive pulmonary disease, which an 'umbrella' title for a group of diseases that cause airflow blockage and breathing-related problems, including emphysema and chronic bronchitis. It can be extremely debilitating, as it was in this case. The lady had been virtually housebound for almost thirteen years to this point, she felt like a prisoner in her own home - defined by her condition. When we first evaluated the nebulisers NARA would use, we looked at portability, this was to allow patients to have more freedom and offered them a quality of life too many of us take for granted. Just over a week after we'd delivered the lady with the equipment, she said she'd been able to go out for the first time on a bus trip. She was overjoyed; she felt her life had been given back to her. Indeed, she said she'd booked a few more similar trips. It was as though a new world and future had been opened up for her. Our decision to help those with nebulisers was certainly vindicated and paying dividends to those we helped.

1994 - 2004

By the end of 1994, we were, more or less, back up to strength and running to near normal speed. Thankfully the trustee had recovered, and work began from our new, and

still current, office at Moulton Park Business Centre, Northampton. It was at this time that we were constantly asked what NARA stood for, when we explained, it left many confused, so we adopted the title, NARA - The Breathing Charity, which was immediately registered with the Charity Commission. We've had no issues since we've used this title.

From the outset of our appeal, we had decided to build up a good rapport with hospitals, surgeries and healthcare professionals. The tangible part of what we do is the provision of medical equipment, but just as important is the support we give to parents and families affected during the time they have our equipment. Having a good relationship with doctors and nurses has helped us provide effective support, and not simply paying lip service. Part of that support too, includes a 24-hour help-line, which our patients have come to rely on, when there's something wrong with their equipment. This support was something we knew we had to have in place from day one and is still in place today.

Our 'approachable' ethos revolved around experiences from the founding parents and increased as the number of patients we'd helped grew too. Where there is illness in any family it doesn't just affect the patient, but others too, be they siblings, or close and wider family members and carers too. From the outset we wanted to foster a feeling, with those we were helping, that they were part of a wider family. Each family had gone through similar problems and experiences, so could exchange views with us, and if they wished, others we were helping too. Most of the equipment we loaned out was taken out by hand, this was to ensure full and proper instruction could be given in how to use it properly.

We'd helped a mother, Marina, with a monitor for her baby, AJ, a few years previous. The monitor was required due to apnoea episodes. Once, AJ had grown much stronger and obviously older, the respiration monitor was no longer required and returned to us. Soon after we'd moved to our new office, Marina contacted us to ask if we could help with a further monitor for her new baby, Curtis, as she'd become quite anxious, and her GP felt it would allay any feeling of anxiety. Again, she kept the monitor for a while until baby Curtis had grown stronger and her anxiety had diminished. In the meantime, both Marina, and her sister, were diagnosed with asthma and both needed nebulisers, which, after the relevant GP's authority was given, were provided. Once Curtis had started nursery school, Marina came to help out at the charity office. A few years later, she and the family moved to Lincolnshire. In 2008, Marina called again, she was expecting another baby and needed to loan a respiration monitor, due to the family history of apnoea and her respiratory issues too. Her GP approved the loan for her new baby Marty, who again kept it until he was older and stronger. We kept in touch and some years



*Above - Marina with baby Curtis
Below - Curtis today*



*AJ with his two children
Barnaby and Flora*

later, AJ had got married and his wife was expecting their first child, Barnaby. Again, due to family respiratory problems, he applied to loan a monitor, which we provided; as we did to his daughter, Flora born a while after. It's good to know from simply helping with baby AJ, in the first instance, we've continued helping the family, into the next generation.

Our next patient we highlight is an elderly lady, Mrs B, from the West Midlands. Well into her seventies, she suffered from severe asthma and other respiratory conditions, that had impacted her life for a number of years. We provided her with a nebuliser, which helped her immensely.



**Top - Mr & Mrs B with their winning ticket
Below - Mr & Mrs B on their holiday**

Around that time, we were organising a raffle to raise funds for the charity, first prize was a four country Alpine tour. Mrs B and her husband purchased tickets and asked for more to sell to family and friends. When the draw was made it was Mr and Mrs B, who'd been drawn out as the winners of the first prize. When we contacted them to pass on the good news, they asked if the prize could be transferred to their son and daughter-in-law, as they hadn't got passports, and they felt too old to go. Two days later, we visited them to take the winning prize over and to check on her nebuliser. We were told, their son had insisted that they get passports and go on the trip. They did and thoroughly enjoyed themselves, especially Mrs B, who said her breathing had improved immeasurably during her stay in the Alps - the air was much cleaner and fresher than in the West Midlands. Sadly, twelve months after

the trip Mrs B passed away, and within a few months Mr B also passed.

Death was something we had learned to become used to, especially dealing with more elderly patients, particularly those with severe respiratory problems. In the case of Mr and Mrs B, we trust that our intervention, not only assisted Mrs B by providing her with the medical equipment she needed, but their trip to the Alps was a high point in the latter years of their lives. They gave us a photo of them enjoying their time near, Neuschwanstein Castle, in Bavaria, Southern Germany - see photos in previous paragraph.

2004 - 2014

One thing we have learned over the course of many years, is how some patients, particularly children, who have severe respiratory conditions to contend with, push themselves and achieve much, despite their illness, which takes us to a young boy, Tommy, from Somerset, who lived with his grandmother. A nebuliser was applied for, due to a change of medication required, and our loaning him the equipment was approved by his GP. Tommy was a keen musician and had a dream of performing professionally upon leaving school. As the years went by, we learned that Tommy, not only refused to allow



**Top - Tommy on stage performing
Below - His band with members of NARA**

his condition to dominate his life, but found singing was actually helping him control his asthma.

About ten years after we had initially loaned Tommy his nebuliser, we were invited to attend one of his band's concerts. It was a superb evening, and we were amazed how Tommy had well and truly got the better of his health issues. He told us that, "Singing has become one of my exercises to combat asthma."

One of our long-term patients, Indira, a lady in her sixties living in the Staffordshire, came to us suffering from bronchiectasis, a condition the NHS say, 'is where the airways of the lungs become widened, leading to a build-up of excess mucus that can make the lungs more vulnerable to infection' and fibrosis, or scarring of the lungs. Her conditions meant we had to provide her with more specialised equipment, in addition to a more 'run of the mill' machine. This was because, from time to time, when her breathing became impaired, and significantly worsened, her medication needed to be administered sonically, meaning it would take less effort for her to ingest, as compared to a normal nebuliser. It also gave her the freedom to lead a reasonably 'normal' life. This lady has been with us for ten years now, and she sincerely thanks us for our assistance and support.

Another elderly lady, Marion, from Hampshire, who is sadly no longer with us, applied for a nebuliser due to her suffering from severe asthma, which required relevant medication as prescribed by her GP. As her only income was her pension, she lived on limited funds but was so very grateful for our help she insisted on sending us £5 every week, she said, "*It's my way of saying 'thank you' for all your help. While I can give it, please accept it to help your wonderful charity.*" Age and her condition got the better of her and she passed away peacefully in 2013.

Another patient was a new baby, Stanley, from Yorkshire, who needed help firstly with a respiration monitor, which the family had obtained separately from the hospital. However, his condition required a more specialised piece of equipment, an oxygen concentrator - a device that concentrates the



Stanley who needed a portable oxygen concentrator

oxygen from the ambient air by selectively removing nitrogen to supply an oxygen-enriched product gas stream. They are used as medical devices for oxygen therapy in healthcare applications, especially where liquid or pressurized oxygen is too dangerous or inconvenient, such as in the home. The NHS could not provide, or source this equipment, so turned to NARA. This portable equipment for Stanley was to enable him and his family to take a holiday. Like a number of patients, we had never met prior to this but communicated on our social media site. It was an absolute pleasure to meet up with him and all his family.



**Stanley needed a Pulseguard
The sensor is attached to his wrist**

In the coming years, due to his condition, he became one of the first of our patients to use a Pulseguard – see below.

2014 - 2024

During this period our 'go to' respiration monitor, the Graseby MR10, was to be unfortunately discontinued. The manufacturer's had given us the regulatory five-year notice. It was quite a devastating blow, we'd been on the ground floor with this technology, almost from its birth in the early 1980s. Indeed, we had become a resource for the manufacturer when they considered updating and improving the monitors, which saw around four upgrades over 30 years. We were not too sure what we could do to replace the machines; they were our absolute staple. So, a programme was put into place to source a suitable replacement – much easier said than done. Most respiration monitors were used in special care baby units, not in the home. Home devices, which didn't come under the term 'medical equipment' were almost 'ten-a-penny' from High Street retailers, but not good enough in our eyes to fill the void made by the loss of the MR10. These home devices were not challenged by the stringent rules that medical equipment comes under, indeed we've always felt these to be almost 'gimmicks' rather than a valid apnoea alarm. Most other respiration

monitors were good to use in static situations, where babies were in cots or confined receptacles, but not for every day use in the home where baby would be in a pram or carry cot in the back of a car. Almost at the end of this five-year period, we came across a company, Delta, that was developing a similar monitor to the MR10. Unfortunately, undergoing rigorous rules, so the new monitor, which could be termed as medical equipment, meant delay, after delay, whilst the manufacturers dealt with the seemingly endless trials, red tape and bureaucracy – not just in the UK, but under EU regulations too.



The Pulseguard



**The Delta monitor has now replaced
Graseby MR10**

Even though Brexit had happened, rules on medical equipment were still under Europe's legislation. In the meantime, we'd seen a completely new development, using modern electronic technologies, both for sensing a baby's breathing and recording various levels by using a monitor called a Pulseguard, which could operate as an MR10, but in addition gave readings of heart rate and blood oxygen levels too. It was much more expensive than the MR10, but the only device we felt comfortable using, until Delta's monitor was accredited. The Pulseguard, and its new incarnation has been a great asset to use, particularly with older children and those with more complex respiratory issues. Toward the end of this financial period, the Delta monitor was up and running and we were using them – a god send, working as well as the MR10.

We helped another family with a baby, Kaiah, this time from London, as she'd suffered apnoea attacks. This request proved how this condition affected not only, the baby and her parents, but the whole family. Her



Baby Kaiah with her monitor

mother was so grateful for our help, she wrote to us saying, *'I have a child who suffers from apnoea (stops breathing). She was only two weeks old when we found out that she had apnoea, and this has changed the whole family's way of life. I would like to say charities like NARA are a great help - if it wasn't for charities like NARA a lot of people would be left helpless. So, if you can please do, (help them) you're not just helping a child, you're helping a child's family to have as near as possible normal life.'*

Another aspect of support we were asked to provide was palliative care, for those at the end of their life, no matter of their age, who wish to spend their last days close to their family and those dear to them, at home rather than in hospital. We had a patient from Cambridgeshire, John, who was in his early



**Palliative Care
Dignity in their last days**

fifties, he's been diagnosed with a terminal condition, but needed a nebuliser to return home for his last days. We did this during the pandemic, but not whilst the restrictions were in place. We gave the equipment to John's wife on the Friday evening, he was due to come home on the Saturday morning. On the Monday morning, we had a call from the family to say that John had passed just a few short hours after he'd arrived home. He'd used the nebuliser a couple of times, and he was so very thankful that his final breath was taken within his own surroundings. His wife later told us we'd provided a short, but very necessary service for John and the extended family. The family generously raised funds for us, to go towards more nebulisers for similar patients and their families.

Forty-year summary

Summing up the last forty years, although it's somewhat of a cliché, we have seen our initial appeal grow 'from a little acorn to a big

oak tree'. Over the years we've been able to provide many thousands of patients with medical equipment and support, not only to them, but extending to their families too. We've given advice to many more thousands too. We can see the positive difference our charity has made during this time to so many lives. With regard to the monitors, countless parents have told us their baby would have died without our intervening in providing a respiration monitor. Those who have had nebulisers supplied by our charity have said their quality of life has significantly improved since using our equipment. Indeed, very recently, Mr P, from Northamptonshire, whose elderly wife has severe breathing difficulties, amongst a catalogue of other health issues, said, *"Thank you for providing the nebuliser, I know it's the reason my wife is still here, without it I would have lost her months ago."* It's so very satisfying to know our charity has worked very hard, over the past forty years, making a significant difference to many lives. Nonetheless, as we've mentioned in many reports previously, we couldn't have achieved anything without financial support from you, the British public, who we can only give our collective applause and sincere thanks.

Currently

And so, to this financial year, which we performed pretty much the same as in previous years. However, with a tough economic landscape, particularly toward the end of the year, we began finding it increasingly more difficult raise the same amount of funds as in previous years. So, we're pleased to exceed our expectations as regards income.

With that in mind, and due to the same reason, we found more people asking for our help, in as much as those who would either have been catered for by the NHS or afford to purchase equipment themselves. So, toward the end of our financial year, with the necessary extra workload in both areas to cope with these situations, the Trustees asked our paid member of staff to increase their hours of work, which from the beginning of March 2024 they agreed. Whilst more expensive, we're sure this extra help will pay dividends on all fronts in the coming months.

During this year we have provided medical equipment to over 300 new patients, as well as providing continued help and support to our 1,200 plus long term patients too. Long term patients are those we help for three years or more, they wouldn't necessarily include babies on monitors, who have their equipment for no more than two years – except in exceptional circumstances, nor would it include many of our palliative patients either.

Typical of the patients we helped during this period were a baby, Cassian, living with his parents in the Midlands, and another lady, Pravina, who was referred to us by her Respiratory Unit.



**Cassian having a cuddle
Suffered from GORD**

Cassian's parents approached us as he'd been quite poorly and had made several visits to their local A&E to find he was suffering from gastro-oesophageal reflux disease (GORD), which is a common condition, where acid from the stomach leaks up into the oesophagus, or gullet. It usually occurs as a result of the ring of muscle at the bottom of the oesophagus becoming weakened. It causes symptoms such as heartburn and an unpleasant taste in the back of the mouth. It may just be an occasional nuisance for some people, but for others it can be severe. In Cassian's case doctors were concerned it may induce apnoea attacks, and he'd stop breathing. A respiration monitor was approved for him to use during this difficult period, which was thought to be temporary and may improve with as he developed with age. We provided a monitor and to date, it's been a terrific reassurance to his worried and anxious parents. Indeed, his parents had this to say, *"Thank you so much, I don't know what we would have done without your help. If anyone wants a new charity to donate to, donate to NARA, they are literally saving lives every day."*

On the nebuliser side of things, a typical patient was Pravina, an elderly lady with an unusual condition. She applied for a nebuliser



Pravina with her nebuliser attached

as she suffers, interstitial lung disease (ILD) – which the NHS describe as, 'a term for a group of conditions that cause inflammation and scarring in your lungs. Symptoms of ILD include shortness of breath and a dry cough. ILD can be caused by medication, radiation therapy, connective tissue diseases or inhaling harmful substances. Lung damage caused by ILD is often irreversible.'

Although she has only been with us a short time, she has needed special care and attention and has been visited by our support team regularly since having the equipment.

Finally, we leave you with a word from a daughter whose mum wanted to spend her last days at home. Her request came like this, *"Good morning, I have been provided with your information by the hospital to contact with regards to obtain a nebuliser for my mum. She has end stage COPD, Lung Cancer and is being treated for a current pulmonary embolism and chest infection. Mum is adamant that she wishes to die at home and doctors are happy that she is currently stable enough to get home but would like her to have a nebuliser at home, which the hospital is no longer able to provide."* That was on June 23, 2023. We delivered her nebuliser by hand, but just a couple of days later we received this message, *"Good morning, I'd like to say a big Thank you for arranging and delivering a nebuliser for my mum. Mum passed away peacefully this morning as per her wishes with her family all around her. Thank you so much"* R L, June 28, 2023. A very short loan of equipment, but very necessary for this mum's dignified passing

As can be seen above, now, we're not restricted, as the past two years with Covid lockdowns, we're able to get out and about in the community once again and visit those needing our help. In total we made 407 visits to patients, which was very satisfying and rewarding, nevertheless, next year we want to increase that work if possible.

We took well over 2,500 calls, many needing and receiving tangible help and others simply wanting advice. And spent almost 1,500 hours on social media liaising with patients, their families and a good number of healthcare professionals too.



NARA - The Breathing Charity

One of our social media sites

These are just a few of the typical requests we've had during this year:-

"Hello, I have just spoken with one of your colleagues about the provision of a Nebuliser

for a patient I have under my care who would benefit from the use of a nebuliser. This lady has lung cancer and is also currently recovering from a viral infection and her cough, breathing and secretions are difficult but were helped considerably in hospital with a nebuliser. This lady has now been discharged home without a nebuliser and is struggling."

We provided the necessary nebuliser and received the following message.

"Thank you for organising provision of the equipment she needs, which I really appreciate, Thank you very much." – from a Palliative Physiotherapist (June 2023)

Another request, *"Dear colleagues, please can you help? We have a patient who has a 'trachy' (a tracheotomy - a procedure where a hole is made at the front of the neck. A tube is inserted through the opening and into the windpipe (trachea) to help you breathe.) He is in need of a new Nebuliser mask for his Trachy, his current mask is deteriorating."* Many Thanks from a Respiratory Nurse Specialist (September 2023)

Lastly, this request for 'end of life' care, *"Hi, I was wondering if you may consider sending a Nebuliser Compressor to one of our palliative patients? Your details were given to me by my Respiratory colleague. Many Thanks."* - Respiratory Nurse (October 2023)

And we constantly receive messages of thanks, such as:-

"Parents in the situation we were in or worse are out there, needing help, needing equipment, the NHS, is pushed financially to its limits and charities such as NARA are becoming vital."

"This lady and her team are amazing they work so hard; they loaned us a monitor for our grandson as his father stopped breathing as a baby and I had to resuscitate him. He has also been diagnosed with a genetic heart condition that is very hard to spot in babies. NARA is always available to talk to and we are so grateful, thank goodness our grandson is 2 now xx."

"Cannot Thank you enough for all the love and support we continue to get from NARA I can now sleep easy and know my baby is safe - if anything isn't right his machine lets us know - his health is very up and down but we know if in doubt we can always call on you guys."

"Without NARA I literally don't know where we would have turned. The NHS doesn't fund medical grade apnoea monitors for children like J. Without NARA I dread to think what could have happened. They are there for us - a lifeline and we Thank you for every penny you donate to them."

Financial

Overall, despite the quite bleak economic horizon, we raised more money this year than we did in the previous year. Although we could be described as a small hand-in-mouth charity, our aim each year is to try and raise £100,000 for our projected funding. Exceeding is great, under achieving, would cause

pressure, but not severe as we operate within our means. We believe this year's success goes hand in hand with the lifting of all restrictions that were put on individuals and businesses due to the Covid pandemic. As we've mentioned in a previous report, it was like coming out of the darkness into the light.

However, we're not too sure that increase is sustainable in the next year, particularly with an election due, anytime between the summer and Christmas. As we've seen over a number of years, an election, with a possible change of government, can cause an air of caution and uncertainty on the fiscal front.

Whatever the future holds, we at NARA, believe that with our minimal financial obligations, and outgoings, i.e. low administrative costs and commitments, feel we will be in a very positive position whatever the outcome.

Over the years, we've always be able to spend at the very least 80 pence in every £1 on the main objectives of the charity - in fact, in many years, it has been significantly above that. This year, we raised £123,074, spending £108,691 on our main objectives giving an outcome of 88 pence for every £1 raised.

Our total expenditure on the main objectives included purchasing hundreds of pieces of new equipment, including a full spectrum of different nebulisers – both mains and portable, apnoea monitors and other specialised equipment, together with all necessary disposable spares and accessories. We also had to dispose of 45 pieces of equipment from our stock, due to age, fair wear and tear - some nebulisers run up to six times a day, 7 days a week – and includes a number of others, which were taken out of service due to the possibility of cross contamination. We take no chances.

Each patient, together with other members of their family, is offered our support, that means being there for them when things go wrong, or they feel they need someone to talk to. As previously mentioned, our work also includes supporting many long-term patients too, so, for a small charity our outreach is far and wide.



We'd like to take this opportunity to say thank you to a number of supporters, companies who have been with us for thirty years, or more, including, the Morelli Group in London, Jacks Transport in Leicester, and Ludlow Motors in Ludlow. Thanks too to the

following Trusts, the **Eric Tolson Charitable Trust, The Gilander Foundation, The Tula Trust and The Strangward Trust.**

We would also like to express our thanks to **The Sporting Bears and Kimbolton Country Fayre** for their continued financial support too - they've helped now for almost ten years.



Sporting Bears Motor Club
Driving for Charity



There are many more who deserve thanks, but in the main, they wish to remain anonymous, so we respect their wishes.

Conclusion

Forty years is a long time, and we've seen our charity grow, mature, and develop within the current needs and requirements of the day, and positively touching countless lives, of all ages, across the length and breadth of our country. Many times, those enquiring for help, especially when they first contact us, are at their wits end, feeling deep in the depths of despair. Our aim is to support them through whatever difficulties they have, ensuring we can help them within the confines of our charity guidelines. One thing is for sure, we do not let the race, creed, or colour of anyone requesting our help, influence any decision we arrive at, nor does their sexuality, or social standing come into question either. We're here to help all we can. As you can see from the body of our report, it's always to try to improve our patient's, and indeed their family's, quality of life. Helping to release them from the bonds their illness restricts them to. In the main, we have succeeded, but as you've read, on a few occasions things can, very sadly, conclude in the opposite direction.

Initially, we only dealt with babies and small children, but as our charity has evolved it has embraced all ages, from those at the very start of their lives, to those in their twilight years. Due to this we've had to accept death as a fundamental process of life, but we trust our intervention, assistance and

provision of medical equipment has gone some way to make their last days more bearable.

In the past ten years too, by helping those needing palliative care, we have helped a number of those, close to the end of life, leave this world around family, rather than on a hospital ward. In the recent COVID years, we helped many stay clear of hospital, especially when infection rates were at their peak.

Our work has also kept us at the forefront of assessing new technology and medical equipment available to support those affected by chronic respiratory ailments. We believe,

in the main, we have been able to select the most appropriate equipment for the patient's needs. Our support package also ensures that should a patient's requirements change, then alternative, or additional equipment can be supplied.

As we enter our fifth decade, we feel we are as relevant today as we were when we first began, if not more so, given firstly, the help now given to patients of all ages, from birth to advancing years. And, secondly, the role we played during the Covid years, and indeed since. We have become the 'go to' charity for many hospitals, especially

respiratory units in many parts of the country. We believe our sustainability has passed many obstacles over the past forty years, and significantly tested throughout the past five years, especially with the pressures and rigours of the pandemic, which saw our charity stretched on a number of fronts, both financially and as an effective body offering help, not only to individuals in a period of crisis, but as a credible support to the NHS in their hour of need too. Yes, we were really pushed, but survived, which the Trustees are proud to have achieved. So, it's onwards and upwards to our Golden Anniversary in 2034.

Sometimes, all they need is the
air that they breathe



THE PROCESS OF HELPING OUR PATIENTS



Prospective patients read what we offer either through our website, or reading our information leaflet, or via their GP or health professional



We're then contacted by phone, Email, or letter. Our staff take full details to determine how and if we can help.



Once we agree on a course of action, we ask the GP or healthcare professional responsible for the patient to sign an authorisation form. Once complete we can pack the equipment ready to deliver



Delivery of the equipment is usually via courier, Royal Mail, or our own representatives. We offer a 24 hour helpline to assist patients set up and enable them to keep their equipment in good working order



Once the equipment is received, our patients are called regularly to ensure all is working well





FINANCIAL YEAR ENDING 30th APRIL 2024

NARA - Annual Charity Accounts

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033



Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Paul Connolly, FCCA. The Tax Shop Group Ltd G14, Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Independent Examiner's Report

Report to the trustees	National Association for the Relief of Apnoea		
On accounts for the year ended	30th April 2024		
Charity number	327033		
Set out on pages	Pages 3 to 6 inclusive.		
Responsibilities and basis of report	<p>I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/04/2024.</p> <p>As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").</p> <p>I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.</p>		
Independent examiner's statement	<p>I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:</p> <ul style="list-style-type: none"> - the accounting records were not kept in accordance with section 130 of the Charities Act; or - the accounts did not accord with the accounting records; or - the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination. <p>I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.</p>		
Signed:		Date:	05/02/25
Name:	Paul Connolly, FCCA.		
Relevant professional qualification(s) or body	The Association of Chartered Certified Accountants		
Address	G14, Moulton Park Business Centre, Redhouse Road, Northampton, NN3 6AQ.		

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Statement of Financial Activities for the Year Ended 30 April 2024

Incoming Resources	Notes	2024 (£)	2023 (£)
Donations from Grants, Trusts, Companies and Individuals	2	123,074	111,008
Direct Charitable Expenditure			
Medical Equipment care and support		108,691	84,576
Other Expenditure			
Fundraising Costs		2,563	2,694
Management and Administration of the Charity	3	14,100	12,229
Total Expenditure		125,355	99,499
Loss on value of monitors			
Expenditure after exceptional costs		<u>125,355</u>	<u>99,499</u>
Net Movement in Funds for the Year		(2,281)	11,509
Total Funds Brought Forward		39,248	27,739
Total Funds Carried Forward		36,967	39,248

There were no recognised gains or losses for 2024 other than those included in the Statement of Financial Activities.


The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2024

	Notes	2024 (£)	2023 (£)
Fixed Assets		36,119	30,094
Current Assets			
Cash at Bank and In Hand		7,193	9,574
Current Liabilities	5	(320)	(420)
Total Assets less Current Liabilities		<u>42,992</u>	<u>39,248</u>
Capital			
Unrestricted Funds		<u>42,992</u>	<u>39,248</u>
Total Funds Carried Forward			

Approved by the trustees on 23rd Feb 25 and signed on their behalf



Trustee

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts

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: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014

The charity has taken advantage of the exemption in Financial Reporting Standard 102 (FRS 102) from the requirement to produce a cash flow 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.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts (continued)

2. Income	2024 (£)	2023 (£)
From Covid Savings Fund	0	500
Donations	122,854	109,893
Medical contribution	220	615
Total	<u>123,074</u>	<u>111,008</u>

3. Administration Expenditure	2024 (£)	2023 (£)
Office Rent and Services	8,880	7,221
Administration staff	4,800	4,588
Independent Examination	420	420
Total	<u>14,100</u>	<u>12,229</u>

4. Staff Costs

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

	2024 (£)	2023 (£)
Wages and Salaries	<u>4,800</u>	<u>4,588</u>

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

	2024 (£)	2023 (£)
Administrative	<u>1</u>	<u>1</u>

5. Current Liabilities

	2024 (£)	2023 (£)
Accrual	<u>320</u>	<u>420</u>