



FINANCIAL YEAR ENDING 30<sup>th</sup> APRIL 2023

# NARA - Annual Charity Report

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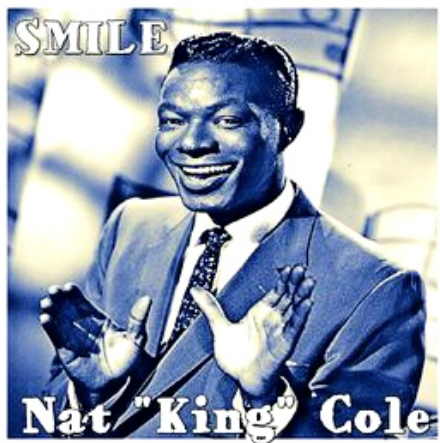
## NARA Annual Report - 1<sup>st</sup> May 2022 to 30<sup>th</sup> April 2023



**F**ollowing on from the previous two years blighted by Covid lockdowns and restrictions, we entered our new financial year in May 2022 with fresh hope, energy and optimism that the world would return to a relative normality. However, at that time, with war in Ukraine following Russia's invasion, a new struggle was underway and again on a global basis. The war saw an already pandemic battered world, now suffering shortages of fuel and food culminating in the prospect of a financial crisis on the horizon that would affect each and everyone of us, the UK being no exception. Increased fuel costs inevitably saw everyday living expenses rise on a weekly basis, so whilst free of the affects of a global pandemic, we, like many others, had new challenges ahead. Charities like ours rely on the generosity of others, with financial belts being tightened across the board, we knew we'd have another difficult year, but had to soldier through. We had responsibilities to those we were helping to ensure our care for them continued unhindered, we also knew they'd be an increased influx of others wishing to draw on our services in the weeks and months ahead.

It's at times like these when we look around and realise that many of those who suffer on a daily basis wear the greatest smiles. If we thought we were having a bad day, some of our patients face daily challenges, but almost always with a smile. So, it was no time for us to be glum, but to take inspiration from some of those we help whose lives are compromised by their condition and health each and every hour of the day.

At times like these, perhaps we could consider the lyrics of a song attributed to the late great Charlie Chaplin, and sung by Nat King Cole, simply called Smile. It's worth reminding you of them here,



*Smile though your heart is aching  
Smile even though it's breaking  
When there are clouds in the sky,  
you'll get by  
If you smile through your fear and sorrow  
Smile and maybe tomorrow  
You'll see the sun come shining through  
for you  
Light up your face with gladness  
Hide every trace of sadness  
Although a tear may be ever so near  
That's the time you must keep on trying  
Smile, what's the use of crying?  
You'll find that life is still worthwhile  
If you just smile  
That's the time you must keep on trying  
Smile, what's the use of crying?  
You'll find that life is still worthwhile  
If you just smile*

Over the life of the charity we have seen many others whose plight and fight for life has been simply amazing. They try to make the

best of every day and every minute of every day. Living a life dictated to you by debilitating medical conditions, or severe disabilities rather than depressing them seems to simply spur them on through their individual adversities. Ruth lives by the mantra, quoted by American historian Alice Morse Earle, 'Every day may not be good, but there's something good in every day.'

During the course of this financial year we have helped many patients of all ages, with varying respiratory conditions across all regions of the UK. Here are just a few examples.

As mentioned above, we have a number of patients in our care who suffer life limiting conditions, however, despite this, on many occasions they smile through their pain. Indeed, visit any children's ward in any hospital and you'll see that despite their health issues many of these children have the brightest of smiles. It's this action, through the plight of their pain we draw inspiration to do the things we do to help them through their difficulties.

One of our most inspirational patients is a young lady called Ruth. She has given us permission to share her story with you. So, in her own words, here it is:-



*'Hey, There! I'm Ruth. I am 29 years old and I live life to the absolute fullest with fun challenges, adventures, many projects on the go and very importantly a bucket list to complete. I want to share my love, passion, and happiness with the world but beyond that positivity, I also work hard on showing the raw, real reality of trying to live life to the full whilst also living with EDS (Ehlers-Danlos Syndrome) and other multiple chronic illnesses, which together for me are life-threatening and ultimately are shortening my life. But that will not stop me and if anything, it just makes me want to grab life and all opportunities I can even more.'*

Ruth contributes to her vlog through various social media channels. Posting on her site 'Just Keep Swimming with Ruth and Willow (her dog). She introduces the site as, 'Making every moment count with my family,

friends and incredible assistance dog Willow by my side. Follow me through the highs, lows and everything in between and when you start to struggle just remember to.. #Justkeepsfloating, or alternatively she suggests #andifyoucantswimjustfloat This post she sent out in April 2023 is typical of her courage,

*'The golden hour really does make the difference between life and death.*

*The last 13 days since I've updated on here I wish I could say has been because I've been busy living but unfortunately I've been busy trying to stay alive.*



*The good thing?  
I survived.*

*This is how one infection can spread, turn to sepsis and into septic shock. (I unfortunately have underlying complications which make me a huge risk for infections).*

*But sepsis can be and is fatal. I'm so lucky to be alive right now and I'm trying not to cry with help doing this but please don't take any moment for granted.*

*I love you all so much. (Yes I'm a sappy so and so and I always will be! #sorrynotsorry)*

*To you all, thank you, you know who you are and I can't explain just the difference your ongoing support it makes and means. Things are far from perfect and this is what makes my ongoing care and treatments so incredibly complicated.*

*But the main aim is to get me back home and get back some quality time and quality of life back into me (though it is really hard knowing the focus is changing) and most importantly to us as a family to make memories, (non medical ones).*

*But right now after 13 very long days (not all I can recall, and there isn't many photos because, too be Frank we were too busy trying to keep me alive) and I'm just so grateful to be stable as it really was touch and go at points, yes I should be used to it by now as I live knowing I'm living on limited time but still, it never gets any easier knowing any day could be your last and knowing my parents have to watch that is heartbreaking. Mum didn't leave my side, didn't sleep for days but the teams including ICU and critical care, surgeons and*

*anaesthetists and all the wonderful nurses saved me, saved us, a miracle or not I don't know I just know I'm lucky to be alive and writing this.*

*Just from me, hug your loved ones a little tighter tonight.*

*Any questions on sepsis or septic shock just ask or comment below, if I can just raise a little awareness through my story then I will always endeavour to, turning something negative into positive, finding a way your story can help others, we can ALL make an impact, we can all make a little difference. I may not be here for the longest time but I'm definitely here to make the most of what I do have time.*

*But for now, rest, breathe and rest.*

*Thank you again for staying by our side. I love you all, so much.*

*All our love, Ruth, Chris, and Willow of course.'*

We are delighted to announce that Ruth has been nominated for the 'Positive Role Model Award for Disability' in the 2023 National Diversity Awards - something that we feel is fully deserved for her tireless work in helping others deal and come to terms with their disability, despite her dealing with her own on going issues.

Unfortunately, during this financial year we lost two tiny lives, which whilst painful for us, was much more acute for their immediate families and friends.

The first of these was a little boy affectionately known as JamJam, born with Patau's syndrome, or Trisomy 13.



The condition is described on the NHS website as follows,

*Patau's syndrome is a serious, rare genetic disorder caused by having an additional copy of chromosome 13 in some or all of the body's cells. It's also called trisomy 13. Each cell normally contains 23 pairs of chromosomes, which carry the genes you inherit from your parents. But a baby with Patau's syndrome has three copies of chromosome 13, instead of two. This severely disrupts normal development and, in many cases, results in miscarriage, stillbirth or the baby dying shortly after birth. Babies with Patau's syndrome grow slowly in the womb and have a low birth weight, along with a number of other serious medical problems. Patau's syndrome affects about 1 in every 4,000 births. The risk of having a baby with the syndrome increases*

*with the mother's age. More than nine out of ten children born with Patau's syndrome die during the first year.*

Born in January 2018, from the outset his parents were told that their precious new baby had a severe life limiting condition. NARA became involved with the family after their baby boy had stopped breathing and needed a respiration monitor so they could be made aware if he did it again. The day after delivery we received the following message, 'You guys saved my son's life last night. I cannot believe how your timing was impeccable and made the difference.' Messages like this, that we have received many times in the past, boost out resolve and confirm our actions are making a difference.

As we got to know him and his mother it was clear this little boy was special. Told that her baby would probably not survive pregnancy, after being born the prognosis for Jam Jam was that he'd not live to see his first birthday. He was also born with six fingers, six toes, and was deaf. Also, there was no tangible evidence of eyes, due to an untreatable condition called bilateral anophthalmia. So, his parents were told there was apparently no way that he'd ever have sight. Imagine the elation of his parents when at eight months old he opened his eyelid exposing a black marble - doctors were astounded he had limited sight. His mother described that day as a miracle.

Sadly, despite his continuing feats that defied the odds, in March 2023 his condition



and complex needs overwhelmed him. Nevertheless, although he died just weeks after his fifth birthday, his life was not only an inspiration to all those he came in contact with, but on a broader global basis through a book his mother wrote called, 'Jam Jam Can' about the highs and lows of living with a child with severe disabilities.

One of the reviewers of the book encompassed Jam Jam's life story,

*'A refreshing read and I enjoyed the book and the happy life the little boy with special*

*needs lives despite his disabilities. I recommend this storybook JamJam Can to all mainstream and special needs creche, preschool and nursery/schools across the continents. It is all inclusive and supports diversity as it portrays the main character JamJam as a coloured child. It is nice to see something different in a children's book and I give kudos to the writer who is a mum of a little lovely boy with disability.'*



The second little boy, Isaac, was born in 2021 with heart defects, so his life was, again like Jam Jam, compromised from birth. At just four days old he had an operation and in the days that followed he had another to try and repair a hole in his heart. Quite early on, Isaac's doctor felt he needed an apnoea alarm,



so we stepped in to help by providing the necessary medical equipment and support. Throughout his short life his parents saw that he was a brave little fighter, but sadly neither that, nor the medical treatment he received to resolve the heart defects was enough to save him. He sadly died in 2022 aged just 18 months.

Moving on from our theme, throughout the year our charity provides medical equipment and support throughout the length and breadth of the UK, we also provide a 24hr

helpline for those who are experiencing difficulty with their equipment, those needing help from us for the first time, others simply needing advice, or those who are at a low ebb and feeling vulnerable with their condition and just need someone to talk to. Whatever their issues we are there to help, by providing them with the help and care they need, signposting them to the most appropriate agency for help, or providing that listening ear.

Our helpline is a physical telephone number, or many seek support through our social media platforms, which are seen as vital resources by our patients, their families and carers, particularly when they feel vulnerable.



The social media platforms offer a communication streams, not only with members of our charity team, but also with our patients who share similar conditions. This interaction offers them an additional gateway of support.

Of course, where possible, now that Covid restrictions had been lifted, we resumed our visit to patients ensuring their equipment is up to date and working efficiently, also that it's appropriate for their particular condition.

During this financial year those visits equate to around 400, that's in the region of around eight per week and with many, many miles of travel. During this financial year we had in excess of 1,200 patients, so meeting around a third of them in just one year is something we're very proud of. It's certainly appreciated by our patients.

At this point in previous reports, we have given examples of help given to those with severe respiratory complex conditions and syndromes needing our help, together with the various pieces of equipment, ie; respiration monitors, nebulisers, and other equipment we've supplied to them, authorised by their healthcare professional. This time we feel it would be better to subdivide help given to particular categories of people, ie; children and young people and adults and seniors.

### Children and Young Adults



Our first example is 2 month old baby Bonnie, who suffers apnoea - cessation of breathing - episodes. This patient represents

the original founding of the charity, helping those parents with children who simply forget to breathe. After the usual permissions were granted by the child's GP, we provided the parents with a respiration monitor. This was in July 2022, since then the equipment has been an additional guardian keeping check on Bonnie's breathing and alarming should she stop.

15 year old Ella who has a rare genetic disorder is our next patient. She suffers Sanfilippo syndrome, which is explained by the Sanfilippo Foundation as, '*Sanfilippo Syndrome — also known as Mucopolysaccharidosis type III or MPS III — is a terminal,*



*neurodegenerative rare disease. It causes children to lose all the skills they've gained, suffer seizures and movement disorders, experience pain and suffering, and then die, often before the second decade of life.*

*It is estimated that Sanfilippo Syndrome affects 1 in every 70,000 births. However, the prevalence could be higher. The true number will only be known when Sanfilippo is included in newborn screening.'*

Sadly, Ella is another example of those patients with life limiting conditions as our opening words explain. We provided her with a portable nebuliser, her mother was thrilled and sent this message to us, "*Ella's new portable nebuliser, what a good idea, I had no idea these even existed. This means that she can take it out with us, which is great if Ella starts to struggle with secretions.*"

A young 20 year old man, Ditta, is in a similar position as Ella above, he has Canavan's Syndrome, which is described as follows; '*Canavan disease is a neurological disorder in which the brain degenerates into spongy tissue full of small fluid-filled spaces. It is caused by a mutation in the ASPA gene which makes an enzyme called aspartoacylase. This enzyme is primarily present in oligodendrocytes, contributes to the manufacture of myelin, and is responsible for breaking down (metabolizing) the brain chemical N-acetyl-L-aspartate or N-acetyl-L-aspartic acid. In Canavan disease, many oligodendrocytes do not mature and instead*

*die, leaving nerve cell projections known as axons vulnerable and unable to properly function.*

*Canavan disease causes progressive brain atrophy. There is no cure, nor is there a standard course of treatment. Treatment is symptomatic and supportive. The prognosis for Canavan disease is poor. Death usually occurs before age ten, although some children may survive into their teens and twenties.'*

Our charity has provided Ditta with a nebuliser to help treat respiratory infections he deals with on a regular basis.

13 year old Archie has been a patient of ours for a good number of years now. We've



been providing long-term help with his various and complex needs. Contracting Covid simply added to his problems and he needed new mains and portable nebulisers and replacement specialised apnoea and tremor monitor. Since we've known him, Archie has shown he is a fighter and has achieved much in spite of having a serious operation and dealing with his various illnesses and conditions. He's has an infectious smile too.

Another of our long term patients is Sophie, who we've looked after for almost ten years now. She has requested we provide her with a home spirometer, which will offer her a basic level of screening that utilises bluetooth technology to connect directly to a smart phone. Users can record Peak Flow and FEV1 measurements in the comfort of their own home with the ability to send results electronically to their healthcare advisor. It is designed to be used as a self-monitoring tool for those with a respiratory condition and as a wellness product for the health conscious.

By using this new equipment, Sophie's consultant suggests she may benefit long term from new treatment. We are looking to get this item funded. We also provide Sophie, on a monthly basis, with infusion sets for the administration of her medication. Like Archie, she too has a very infectious smile, despite her many health issues.

Our next patient is a 28 year old young lady, Lydia, who has Allergic Bronchopulmonary Aspergillosis. It is described as, '*a*

condition that causes the patient to develop an allergic response in the airways to *Aspergillus* spores or colonising *Aspergillus* moulds. ABPA is predominantly found in patients with treatment-resistant asthma (although this is not always the case) and cystic fibrosis, and manifests with transient and fleeting pulmonary opacities and bronchiectasis.

It is estimated to affect 2.5 – 5% of those people with bronchial asthma, which equates to 125,000 – 250,000 cases, though the number diagnosed is far lower. Much better diagnostics are needed! Diagnosis can be very slow, with some estimates giving an average of 10 years (and up to 20 years) between the first symptoms and final diagnosis, a claim which is certainly borne out by the comments of some existing ABPA patients.

Typically ABPA is predominantly associated with poorly controlled asthma but can also include excessive mucus production, mucous plugs, coughing, haemoptysis, bronchiectasis, low-grade fever, weight loss and malaise.'

Again, we have provided Lydia with a nebuliser to treat a number of her respiratory infections and conditions.

Another young lady, 25 year old Koya, suffers severe asthma. When she contacted us she was struggling to cope with her condition and asked if we could help in any way. Again, a nebuliser was sent to her. She sent us the following message of thanks, *"Thank you for everything! I honestly cant put into words how much I appreciate what you guys have done. Thank you so much for getting me the nebuliser - it came so quick! These past couple of weeks have been extra trying, feeling a if I'm running off half a lung - it's not been fun. Honestly, thank you so very much."*

A patient who needed a more sophisticated nebuliser, 20 year old Edward, suffers Leopard, or Noonan Syndrome. *'Noonan syndrome is caused by a fault in one of several genes. At least eight different faulty genes have been linked to the condition so far. In some cases, the faulty gene associated with Noonan syndrome is inherited from one of the child's parents. The parent with the faulty gene may or may not have obvious features of the condition themselves. Only one parent needs to carry the fault to pass it on and each child they have has a 50% chance of being born with the condition. In other cases, the condition is caused by a new genetic fault that isn't inherited from either parent. In these cases, the chance of the parents having another child with Noonan syndrome is very small. It's estimated that between 1 in 1,000 and 1 in 2,500 children are born with Noonan syndrome. It affects both sexes and all ethnic groups equally.'*

The nebuliser we provided cost around £1,000, but is only used in exceptional circumstances. It is the most efficient device for dispensing medication and antibiotics.

Our next patients are babies, the first is a mum who needed a monitor for one of her



children born sometime after she had tragically suffered the loss of a previous baby. Losing a baby is something that most of us can only imagine, but to those who are unfortunate to suffer such a loss, that loss is immeasurable. As we helped her successfully with his older sibling, she came back to us again when expecting baby Oakley who was born during the late summer of 2022.

The monitor has helped tremendously in reducing her anxiety and, of course, reassuring her that it would alarm should her baby stop breathing.

Baby Ava was also born premature, she was a poorly baby and had suffered apnoea episodes that needed monitoring. Whilst in hospital there is 24 hour care and support and qualified medical support. Removing your baby from that environment to simply being at home with nothing but mum, dad and



possibly other members of the family is quite daunting. The use of the monitor gives that positive click every time the baby takes a breath, also knowing it will alarm if baby forgets to breathe offers such reassurance. Again, a monitor was provided by us.

Lastly, baby Scarlet, born in early Spring 2023, suffered from a number of respiratory disorders including a floppy larynx when the aryepiglottic folds fall inwards resulting in noisy breathing (stridor), difficulty feeding and sometimes increased effort in breathing.

It is said, if babies with this problem manage to feed well and gain weight then no operation is necessary as it usually goes away without any treatment by the age of 18 months.



We provided Scarlet's parents with a respiration monitor, again to help should she stop breathing.

Many of those parents supplied with respiration monitors have said that without the monitor their baby would have stopped breathing and they would have been unable to intervene, meaning they'd have possibly lost their precious child.

### Older People and Seniors

In this next group of people we highlight some of those older people whose life is blighted by severe respiratory illness and conditions. Many of them have suffered for many years, but as they have grown older their condition has worsened reducing their quality of life. It's restoring some of that quality to these patients that makes our work



so worthwhile on a daily basis.

We begin with 88 year old Pauline who found herself in hospital for 120 days suffering blood clots and severe asthma. On being discharged from hospital she was prescribed with long term antibiotics and needed a nebuliser to administer them. On being given the equipment her daughter wrote this note of thanks, *'Thank you for the delivery and demonstration of the nebuliser for my mother, it was good for her to meet you. Since using it she can say it brings her much relief. Thank you also for your help and support you've given my mother, it is appreciated.'*

Our next patient, 70 year old Christine, was referred to us by her Lung Function Clinic as a person in need of a nebuliser due to her



suffering from COPD, advanced asthma, and emphysema. At this point, it's worth mentioning that we work closely with a number of the UK's respiratory hospitals and their teams responsible for their patient's post hospital treatment. Again, a nebuliser was provided to support her ongoing treatment.

51 year old Caroline came to us in early Autumn of 2022. She suffers from a quite rare condition of tracheobronchomalacia, or TBM, which is described as; *'a condition where there is softening of the cartilage within the walls of your airways. It can affect different parts of your lungs, your windpipe, known as your trachea and your main airways that branch into your lungs, called your bronchi. The cartilage is responsible for keeping the airways open, allowing air to easily move in and out as you breathe.'*

*Breathing in is an active process where the muscles of your diaphragm and rib cage contract to open up space for air to come into*



*the lungs and then they relax which allows the breath out.*

*TBM means that the airways are floppy. When the muscles relax, the airways are unable to stay open fully and they partially close down making it more difficult for the air to move out.*

*If you have phlegm, known as sputum, this will also get stuck if the airways partially close*

*as you breathe out. This will make it more difficult for you to clear the sputum.'*

Caroline also suffers severe asthma, so requires a nebuliser to administer necessary medication. As you can see from her photo, she was a patient we delivered her equipment to her doorstep, but waited in the car for her to pick it up and we used a mobile phone to talk to her to set it up. This was done as a safety exercise for both patient and our staff.

71 year old Helen, is a victim of Covid and now suffers Long Covid, which has compromised much of her health including her breathing. Necessary medication has been prescribed for administration via a nebuliser to assist with her ongoing treatment.

We received this lovely note of thanks from her hospital consultant, *'Thank you for getting in touch, I'm very grateful to you for offering to help our patient. I am hoping that like for many other patients, NARA would be able to make a difference to this lady's life. Best wishes and thanks once again.'*

Just as we have helped some of our children and young adults on a long term basis, we have similarly helped some of our older patients for long periods too. It was our dealings with 62 year old Julie since 1999, that caused concern as she came to us in the wake of her having Covid, chronic asthma and suffering a stroke.

Covid has left many people vulnerable to a range of respiratory conditions that impede their quality of life. Again a nebuliser was provided to assist with her ongoing treatment.

66 year old David was another victim of Covid which left him in a coma. Once recovered from his coma he was left with pneumonia and COPD, these conditions had



a profound effect on his breathing. During this financial year David has been provided with two nebulisers - owing to his infirmity he dropped and broke the original machine, so a new one was given.

Cold and damp weather conditions during late Autumn can be just as difficult for severe asthma sufferers as the pollen in the height of summer. Asthma can be triggered by a



plethora of things that healthy people take very much for granted. 58 year old Nami was one such patient to be affected by the changing climate as a long term sufferer of bronchiectasis. Bronchiectasis is a long-term condition 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. A nebuliser was provided to give her long term treatment.

Our next patient, 62 year old Abida has been supported by us since 2010. The equipment we had previously provided her with was in need of replacement. Typical of similar patients she has suffered COPD and reduced lung function for a good number of years and relies heavily on the equipment and support provided by NARA.

Helped since 2012, 48 year old Paula who suffers brittle asthma, severe breathing problems, and diabetes also needed her equipment updating, as did 58 year old Numtal who has been helped by NARA since 2018. Numtal suffers severe asthma, active invasive sinusitis. The new equipment provided was essential to ensure her nebuliser therapy remains effective.

Kady is a 45 year old lady who has been on our books and given support since 2017, a long term sufferer of COPD and severe asthma has been provided with a wealth of equipment, both portable and mains nebuliser to assist to maintain her with a reasonable quality of health.

Quality of health is something the majority of us take for granted. During the Covid months, it came to the fore that we're probably more vulnerable to health issues than we thought. Many who suffer severe conditions tend to be isolated and become defined by their condition, 50 year old Tracey is one such patient we helped who suffers from anxiety and depression, which is bought on from her long term suffering from severe asthma, COPD and polymyalgia rheumatica.

Lastly, we deal with those who have come to the end of their life and simply want to be amongst family and take their last breath in the comfort of their own home and environment. Where this happens, NARA has stepped in on a number of occasions to ensure a patient's last wish can be granted.

This was the case with 88 year old Irene, who suffered severe COPD, heart failure and diabetes. In November 2022 we were asked to help with a nebuliser so that Irene could leave hospital and live at home for her last days - we agreed. Irene died just before Christmas, but she was surrounded by her family - just as she wished - before she passed away.

### Financial

As we emerged from the Covid lockdowns and entered a year of financial uncertainty, this financial year saw us not only rekindling relationships with long term supporters, but venturing to pastures new for funding, which saw our total income rise to a shade under £10,000 on the last financial year.

In terms of expenditure, that was along the lines of previous years, with small rises across the board in both admin and fundraising. Having said that it still saw us spending 84 pence in every £1 raised on the main objectives of the charity, but given the financial landscape we felt it was prudent to hold on to a significant amount of monies to carry forward to the next year - £9,574, as opposed to just over £3,000 in the previous year. Keeping this money in hand helped us through a number of lean spells when income was not as forthcoming as the historical norm.

It's good to report this time that we can now begin to recycle equipment once again, ie use for more than one patient, once the original patient is finished using it. We had to stop this practice during the Covid months due to cross contamination. Now, we have procedures in place congruent with standard practices in the field of sterilisation of medical equipment for reuse. Had we not had this facility it would have proved extremely difficult to service the increase in patients during this period. This along with the purchase of new equipment has helped us cope with a significant increase of patients.

At this juncture we must extend our grateful thanks to each and everyone who has supported us, be they individuals, groups, businesses, or trusts. Indeed, each and every donor, whatever the size of their donation has helped us immensely to continue or work throughout this financial year - sincere thanks to you all.

We have a great donor base, many have been with us for a good number of years. We appreciate there are those who help who wish to remain anonymous, but of those who have allowed them to name them include the following.

Firstly, **Best at Travel**, who have supported us for the past 29 years, once again



offered their help once again. It's good to be able to count on regular supporters such as these, not that we take their help for granted, but it's the relationship that counts.

Next come two trusts, the first helps our work in Cambridgeshire - the **Alan Boswell Charitable Trust**



### CHARITABLE TRUST

followed by **Charlotte Marshall Charitable Trust** for our patients in Sussex.

As we move forward towards our 40th Anniversary, financially speaking it would appear that we've truly weathered the storms and come out the other side in good health. In 2023/2024 we look to build on these foundations.

### Summary

Whilst these past 12 months have seen us move back to a relative normality. There's no doubt that Covid, or the effect of the pandemic still plays a major part in our everyday life. There's a certain frailty still existing for many who suffer ill health, be they young or old. In our work we have seen the ravages of Covid, with many sufferers coming to us with related respiratory conditions, something they never had suffered prior to Covid.

Others have come to us with other health issues, which doctors are referring to as Long Covid, which is a new condition and still being studied. Recovery from Long Covid varies. Some symptoms can improve quickly and others last longer. The chances of having long-term symptoms does not seem to be linked to how ill you are when you first get

Covid-19. People who had mild symptoms at first can still have long-term problems. Some of the symptoms include, extreme tiredness (fatigue), feeling short of breath, loss of smell, muscle aches, or a number of other problems. Whilst in the main these conditions are not exclusively respiratory, we have seen a tremendous growth in Covid related respiratory problems, hence an overall increase in new patients of almost 300 more.

Strangely, we also noticed that the periods of pandemic lockdowns have seen a significant downturn in premature births, some figure abounding at present suggest around 50,000 less. We are currently awaiting reports from various bodies to confirm these figures and explanations for this phenomena.

As mentioned previously, we were pleased to be able once again to pay regular visits to patients face to face rather than the remote ways we used during the height of the pandemic. In saying this, none of our team, voluntary or otherwise, ever find themselves on a one to one basis with any patient, be they considered vulnerable or not.

The patients we visit are always aware of their allotted day and time of appointment, so they can have other members of their families, or chaperones with them. When visiting patients, we always use appropriate PPE including face masks and coverings as deemed necessary.

Looking forward, 2024 marks our 40th Anniversary since our charity was founded, it doesn't seem possible. In those years we've seen our work build and evolve within the constraints of our constitution.

Our overriding purpose has been to increase the quality of life for our patients, their families and carers. More simply than that, our patients fundamental need, be they young or more senior, is to be able to take a breath.



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

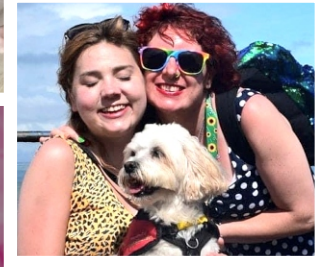


Delivery of the equipment is usually via courier, Royal Mail, or our own representatives. We offer a 24 hour helpline to assist patients set up and enable them to keep their equipment in good working order



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





FINANCIAL YEAR ENDING 30<sup>th</sup> APRIL 2023

# **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](http://naratbc.org.uk) - Email: [info@thebreathingcharity.org.uk](mailto:info@thebreathingcharity.org.uk)  
Registered Charity 327033



*Caring for all generations*

## NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

### Charity Information

<b>Trustees</b>	A Jiggle E Atkins K Jiggle
<b>Charity Number</b>	327033
<b>Charity Offices</b>	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
<b>Examiner</b>	Paul Connolly, FCCA. The Tax Shop Group Ltd G14, Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
<b>Bankers</b>	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**                      **30<sup>th</sup> April 2023**

**Charity number**                              **327033**

**Set out on pages**                              **Pages 3 to 6 inclusive.**

**Responsibilities and basis of report**

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/04/2023.

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").

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.

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:

- 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

**Independent examiner's statement**

- 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.

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.

**Signed:**



**Date:**      **20/02/24**

**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 2023

<b>Incoming Resources</b>	<b>Notes</b>	<b>2023 (£)</b>	<b>2022 (£)</b>
Donations from Grants, Trusts, Companies and Individuals	<b>2</b>	111,008	101,218
<b>Direct Charitable Expenditure</b>			
Medical Equipment care and support		84,576	94,507
<b>Other Expenditure</b>			
Fundraising Costs		2,694	1,728
Management and Administration of the Charity	<b>3</b>	12,229	11,230
<b>Total Expenditure</b>		99,499	107,465
Loss on value of monitors			8,325
Expenditure after exceptional costs		99,499	115,790
<b>Net Movement in Funds for the Year</b>		11,509	(14,572)
<b>Total Funds Brought Forward</b>		27,739	42,311
<b>Total Funds Carried Forward</b>		39,248	27,739

There were no recognised gains or losses for 2023 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 2023**

	<b>Notes</b>	<b>2023 (£)</b>	<b>2022 (£)</b>
<b>Fixed Assets</b>		30,094	25,019
<b>Current Assets</b>			
Cash at Bank and In Hand		9,574	3,140
<b>Current Liabilities</b>	<b>5</b>	(420)	(420)
<b>Total Assets less Current Liabilities</b>		<u>39,248</u>	<u>27,739</u>
<b>Capital</b>			
Unrestricted Funds		<u>39,248</u>	<u>27,739</u>
<b>Total Funds Carried Forward</b>			

Approved by the trustees on 21st Feb 24 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)**

<b>2. Income</b>	<b>2023 (£)</b>	<b>2022 (£)</b>
From Covid Savings Fund	500	0
Donations	109,893	100,738
Medical contribution	615	480
Total	<u>111,008</u>	<u>101,218</u>

<b>3. Administration Expenditure</b>	<b>2023 (£)</b>	<b>2022 (£)</b>
Office Rent and Services	7,221	6,778
Administration staff	4,588	4,032
Independent Examination	420	420
Total	<u>12,229</u>	<u>11,230</u>

**4. Staff Costs**

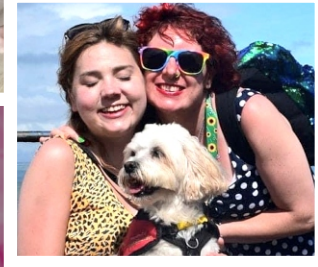
No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	<b>2023 (£)</b>	<b>2022 (£)</b>
Wages and Salaries	<u>4,588</u>	<u>4,032</u>

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

	<b>2023</b>	<b>2022</b>
Administrative	<u>1</u>	<u>1</u>

<b>5. Current Liabilities</b>	<b>2023 (£)</b>	<b>2022 (£)</b>
Accrual	<u>420</u>	<u>420</u>



FINANCIAL YEAR ENDING 30<sup>th</sup> APRIL 2023

# **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](http://naratbc.org.uk) - Email: [info@thebreathingcharity.org.uk](mailto:info@thebreathingcharity.org.uk)  
Registered Charity 327033



*Caring for all generations*

## NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

### Charity Information

<b>Trustees</b>	A Jiggle E Atkins K Jiggle
<b>Charity Number</b>	327033
<b>Charity Offices</b>	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
<b>Examiner</b>	Paul Connolly, FCCA. The Tax Shop Group Ltd G14, Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
<b>Bankers</b>	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**                      **30<sup>th</sup> April 2023**

**Charity number**                              **327033**

**Set out on pages**                              **Pages 3 to 6 inclusive.**

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**Independent examiner's statement**

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**Signed:**



**Date:**      **20/02/24**

**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 2023

<b>Incoming Resources</b>	<b>Notes</b>	<b>2023 (£)</b>	<b>2022 (£)</b>
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There were no recognised gains or losses for 2023 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 2023**

	<b>Notes</b>	<b>2023 (£)</b>	<b>2022 (£)</b>
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Trustee

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# NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

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**NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA**

**Notes to the Accounts (continued)**

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