

## NARA - Annual Charity Report

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

## NARA Annual Report - 1st May 2021 to 30th April 2022



Adue to the spread of the Covid-19 virus, which had blighted lives not simply on a national level, but on a global basis too. The UK government urged people to be patient ahead of the next planned relaxation of the rules mid-May. With the onset of a vaccination programme, and despite the further complication of a South African strain becoming rife, the 17th May saw restrictions relaxed allowing indoor hospitality to reopen with groups of up to six people. By the latter part of June, the government's latest initiative 'Grab a Jab' saw hundreds of venues, including stadiums, shopping centres and theatres, turned into temporary vaccination centres in order to increase the number of people receiving vaccinations. Then on 19th July, the final stage of Covid restrictions were lifted in England, allowing nightclubs to reopen and abolishing social distancing rules, and the wearing of face coverings was no longer required by law.

Against the background of the foregoing, our charity continued to battle through assisting those, already burdened with severe respiratory conditions who were considered one of the most vulnerable of people in the face of the virus. With such a widespread effect, it came as no surprise that some of those patients caught Covid, and became very poorly, some needed hospitalisation, sadly some didn't survive. Nevertheless, NARA played a significant role in keeping many of our patients, old and new, out of hospital and in the relative safety of their own home. We must admit, that the Covid pandemic put a strain on our charity, challenging and restricting the way we obtained and delivered equipment, supported patients, and generally functioned, but we feel with our almost fortyyear experience, and thanks to those we have formed relationships with over the years, we rose and coped well with the demands of the situation. The fragile and unease of returning to a more 'normal' life, protected by immunisation, led many to become more confident with the passage of time. The biggest problem both for us and our patients was complacency, with many thinking it was now 'all over' rather than living beside the virus and its many strains. Again, we managed to pull through, as our headline suggests, by the end of the year we were 'still standing'.

Enough of us 'blowing our own trumpet', let's see what some of our patients said about us as we give an overview of just a handful of those assisted during the year.

#### **Respiration Monitors**

Whilst we were now using the new Delta monitor, the retirement of one of our suppliers saw us able to buy a good number of the older, but still working Graseby MR10 models at a very competitive and discounted price, which was a godsend, especially with our inability to hold or organise fundraising events.

This first case is very sad as the couple approached us some four years after very sadly losing their first daughter who suffered severe cystic fibrosis. The NHS website describes cystic fibrosis as follows, Cystic fibrosis as an inherited condition that causes sticky mucus to build up in the lungs and digestive system. This causes lung infections and problems with digesting food. In the UK, most cases of cystic fibrosis are picked up at birth using the newborn screening heel prick test. Symptoms usually start in early childhood and vary from child to child, but the condition gets slowly worse over time, with the lungs and digestive system becoming increasingly damaged. Treatments are available to help reduce the problems caused by the condition and make it easier to live with, but sadly life expectancy is shortened. After their second daughter, Baby P was born, tests revealed she too had inherited the condition. A monitor was required to check Little P's breathing, during a particularly testing period. Describing their daughter as their 'rainbow miracle' baby,

they offered these words, "With the help of NARA we were given a machine to monitor her breathing and I used until I felt it was ok not to worry as much. Thank you so much to Ann and all the team".



Little P of North-West England

Now we look at a set of twin girls, from South-West England. During their first weeks of life, they developed a problem in that whenever they swallowed, they choked and occasionally stopped breathing altogether. Their worried and extremely anxious mother called us, and we helped by providing them with respiration monitors. Mum sent this message to us when the situation eased and the girls seemed to grow out of the problem, "We are so thankful for all of the help we were given from NARA - when you're at your most anxious and the babies are so little it was so lovely to have somebody listen and understand. They are now very healthy oneyear-olds that are thriving in every way!"



Twin baby girls from the South-West

Another set of twins next, born at 28 weeks, from the North-West. Whilst one of the boys progressed well, the other gave doctors cause for concern in that he suffered haemothorax, this is where blood collects in the space between the chest wall and the lung, making it difficult for the baby to breathe. Affecting the lower section of the left lung a decision was made to remove part of the lung to relieve the problem. Whilst drastic and invasive it was the only way forward. The

parents of the boy contacted us after it was recommended that they have a respiration monitor, post operation, just in case there were further issues. Thankfully, there were no more problems, and the young boy is





Twin boys from North-West Top: Days old - Bottom: More recent

progressing well. The parents said, "we're delighted with the help we received from NARA."

The story of our next patient, five-weekold baby boy, O, from Greater London, is graphically described here by his mother. "Our son was only five weeks old when he suddenly stopped breathing. There was no noise, or choking sound to warn us, we just happened to look down and saw him turning blue in my



Baby O of Greater London

arms. Thankfully on that occasion we were able to resuscitate him. He had a recent diagnosis of a rare chromosome disorder and with many tests pending we were unsure what caused the incident or how likely it was to reoccur. The fear of being unable to protect him from another silent attack was paralyzing. I couldn't see how we would ever be able to sleep, drive, or manage the urgent demands of our potty-training toddler without taking our eyes off our boy. Thankfully NARA was able to loan us an apnoea monitor, which would sound an alarm if he stopped breathing. This gave us so much peace of mind and allowed us to build a much more normal family life together. We will be forever grateful for the loan of this life saving equipment."

We're pleased to say, despite his health problems O is progressing reasonably well.

Another of our very young patients, Baby I, from the South-West of England, had a problem with his internal organs too. In this case, it wasn't his lungs, but his heart and arteries. At just hours old, it was found that his blood wasn't circulating properly, and on



Baby I of South-West England

closer examination he was found to have a hole in his heart. At four days old, surgeons put bands around one artery to restrict the amount of blood flow going to his lungs to allow more blood flow to go to the rest of his body this was done via the chest, the surgery went well. The following day he had another operation, this time this surgery via his groin was to place a stent into his artery which usually closes soon after birth but was needed to continue working to keep his heart pumping. NARA was called upon for this brave and determined little lad to alert his parents should he stop breathing.

#### **Advanced Monitoring**

Regrettably, the pandemic not only took lives, but also hit the fabric of many businesses causing them to close their doors for good. Our supplier of advanced monitoring equipment PulseGuard were one such company. Over a handful of years, using latest technology they'd offered us a more sophisticated form of monitoring breathing,

pulse, and heart rate together with added alarm should the baby suffer an apnoea episode- stop breathing. Not only did it monitor each and every function, but also provided professional healthcare workers with the necessary data logging of bodily activities. Their equipment was used by a number of our younger patients with great success, unlike the respiration monitors, this equipment could monitor patients of all ages. Sadly, the economic strain of the past two years became too much for the company to continue and they closed. Thankfully, members of their staff alerted us to another company that could not only take over running of our existing stock of equipment but introduced us to a new improved system they had developed. So, during the course of the year, we were able to transfer all our current patients over to the new system.

To give an example, we look at the case of a toddler, named J, from the West-Midlands, who we mentioned in our last report suffering from West's Syndrome, which is a constellation of symptoms characterized by epileptic/infantile spasms, abnormal brain wave patterns called hypsarrhythmia and



**Toddler J of the West-Midlands** 

intellectual disability. Three-year-old J, had used one of the original PulseGuard monitors, then seamlessly transferred to one of the new units. Under the care of another agency, one of the nurses involved with the family commented, "Thank you for all your help with 'J', you've got no idea to the extent of the help you've given. Not only have you help a very sick boy, but you've helped mum enormously too." The boy's mum added, "the equipment has been our saviour, and I can't thank you enough as a mum to know my baby makes it through the night."

#### Nebulisers

Our 'bread and butter' work over the past twenty-five years has been the provision of nebulisers, which atomise medications so they may be administered with relevant ease. It's possibly the most vital piece of our patient's armour in their battle with their differing respiratory conditions.

Firstly, a young lady, A-C from Wales, who was recommended to us by one of our

patients in Yorkshire. It's comforting to know our patients have so much confidence in us. Living under the care of a hospice for almost more than two-thirds her life, A-C suffers from a number of health conditions, caused by degenerative multi-function-disease. Much of her body is compromised by this condition including her breathing, she suffers severe



A-C of Wales

asthma and epilepsy too.

She required a nebuliser to administer various necessary doses of medications. After the usual authorisations from her healthcare professionals, we provided her with the equipment she required. Overjoyed with our help, she went on social media posting a film of her opening her new nebuliser, ending with the tag line, "thank you to the incredible NARA - The Breathing Charity".

We're often contacted by NHS Respiratory Community Teams from various regions of the UK to help their patients by the provision of a nebuliser. One such man helped was 63-year-old Mr N, who suffers from chronic obstructive pulmonary disease (COPD). The NHS website describes COPD as, 'the name for a group of lung conditions that cause breathing difficulties. The breathing problems tend to get gradually worse over time and can limit your normal activities, although treatment can help keep the condition under control.' Providing Mr N with a nebuliser allows him to remain within his home environment rather than being hospitalised.

Another patient recommended by a palliative nurse from another local respiratory team was a middle-aged lady of the traveller community. Her health issues included breathing difficulties, and a number of mental health problems. Being a member of the travellers' community led to her not necessarily having access to mains electricity. We therefore had to look for a good quality portable machine, which could be used or charged on the mains, or used via a battery. Once the equipment was delivered, the nurse made the following comment, 'Thank you so much again for everything you do, you go above and beyond to help our patients.'

Next up was a 57-year-old lady again from East Anglia, who suffers bouts of severe asthma, plus other health issues such as lupus, coronary heart disease, and depression was referred to us by the National Asthma Campaign as she needed a nebuliser and they do not provide equipment. We went through our usual channels and sought approval with her GP and we're able to help. She was absolutely delighted with our response, "I am so grateful for the help and support that I've had from this charity, following a bad bout of asthma. When I contacted them, I was desperate for help. I needed an up-to-date nebuliser, which I now have at home and has greatly improved my life, by making it so much more manageable. The help I've received has been excellent and the people from the charity are friendly and understanding. I would definitely recommend this charity to anyone in need."

We had another request for a specific piece of equipment, this time it was for a young seven-year-old boy, O, from South-West England. He suffered severe autism, complex health issues, global development delay, severe asthma and eczema. Due to his autism, noise from one of our usual nebulisers caused the lad more problems, so we had to provided him with a silent device, so medication could be administered without problems. His mum said, "O struggles with asthma and quick onset laboured breathing from allergies, he is mentally disabled and is mentally around the age of 11 months, so has no understanding of waiting in a hospital room for a nebuliser, So, NARA providing one that we could use in the comfort of our own home has been an absolute life saver. O also has autism and sensory processing disorder, and Ann went above and beyond when she found us a silent one that reduces stress and anxiety whilst using the much-needed piece of equipment. Thanks so much NARA. I have recommended you to the special school my son goes to."



Seven-year-old O of South-West England



Mr E of the East-Midlands

Lastly, from time to time we deal with people who have social and domestic issues, this was the case of 65-year-old Mr E of the East Midlands, who lived in sheltered accommodation. Also suffering from COPD, he needed a nebuliser to administer his medication. Not only was he, but the sheltered housing group also thanked us for our intervention and provision of equipment.

#### Other equipment

In more recent years we've provided infusion sets to those patients who need medication administered via a manual or automatic syringe pump. Again our patient, a young lady from Yorkshire, referred her good friend R to us to see if we could provide her with infusion sets. R, a young lady from South-East England, suffers Addison's Disease and Ehlers-Danlos syndrome are conditions which affect a number of vital organs, which in turn compromise many bodily functions including breathing.

Delighted that we were able to help her, R said, "I am so grateful to NARA and the work it does. It provides me monthly with vital medical equipment that I need and unfortunately falls through the gap between my hospital and GP. Without this I would have to pay for these things and when you have serious long term medical conditions there is so much you have to manage but with NARA's help, I can relax knowing I can get my medical equipment safely and regularly."

#### **Financial**

There's no doubt, over the past two financial years, like many other organisations, our charity has encountered some of the darkest months. Having to not only pare-back



A-C of Wales and R of South-East England have become good friends

on some of our methods of supporting our patients, but fundraising events too. This in turn left us a little short of our overall income for the year, in relation to previous years. It would have been foolhardy to have expected any different.

However, thanks to some excellent relationships built up over almost forty years of our existence with a good number of our supporters, and being able to carry over almost £10,000 from 2020-2021, the blow was somewhat cushioned to what it could have been.

In relation to obtaining new equipment we were not only affected by the virus, but also the fall out of Brexit, which reduced the supply of equipment as new checks and systems were adopted when importing goods, leaving us to use new retailers and suppliers.

We were very fortunate to be offered some low-cost equipment, both nebulisers and respiration monitors by several retailers, plus we were given an ample supply of personal protective equipment (PPE), by another business working out of the same premises as we do.

Throughout the course of the financial year, like many similar charitable organisations we were offered loans to support us throughout the difficulties, but we declined any such assistance as accepting it would have meant us repaying whatever we had loaned and therefore compromising future finances. We felt it better to weather the storm, if we possibly could.

So, again, thankfully, with the cooperation of our suppliers, and the generosity of our supporters we were able to pull through.

At this juncture, although a good number wanted to remain anonymous, it's worth highlighting a couple of the many who donated to our cause.





A fun evening at the Empress Club, New Brighton raised £1,300

Firstly, special thanks to the grandmother of one of our patients, who in March 2022 raised £1,300, by organising a charity 'Rock Night' together with members of the Empress Club, New Brighton, in memory of her late friend.



Secondly, to Brayleys car dealership, who have supported our charity for a good number of years and have, according to their social media post, been proud to do so. It's building relationships with businesses like Brayleys that greatly assist our economic survival. Thank you.

# T&C PRECISION LTD

Another company that has supported our charity for almost 30 years is T&C Precision Ltd, again it's working closely with companies such as theirs that offer long term financial stability to our small, but necessary charity.

#### The Gilbert Lane Trust

Lastly, but by no means least, the Gilbert Lane Trust, once again supported our work in Lincolnshire. We're truly grateful for their kind assistance, which is a life-line for our patients in that area.

#### Summary

As has been the theme of this report, thanks to our working with all those we come into contact with during the course of our work, be it patient, medical professional, supplier, or financial supporter our robustness has seen us through possibly the worse and darkest months since our founding. Together we have all done our bit, even going the extra mile, to achieve our goals, for which we are most grateful and thankful. Whilst the next twelve months will no doubt raise more issues, hopefully, these will not include any further restrictions due to the virus. Having said that, two of our number fell victim to the virus during the latter stages of the financial year and had to spend time isolating.

Again, during the lockdowns particularly we had to adopt new methods of delivering equipment and supporting patients. Our normal methods of delivering equipment, where we visit the patient, obviously had to be changed. Instead of actually going into their residence and showing them how to set the equipment up, we delivered it to the doorstep, return to our vehicle, call the patient and walk them through step-by-step in how to set up their equipment. Whilst not ideal, it was the best we could do under the circumstances. In certain instances, it did have a positive outcome as a number of them became more au-fait with what they were using, understanding how it worked. This was very useful, should they encounter difficulties at a later date.

Otherwise, if the foregoing wasn't possible, we gave the equipment to the patient's healthcare professional for them to set up, which worked well too. However, with healthcare professionals stretched to the limit

dealing with the virus, it wasn't always possible.

Supporting patients too, in excess of 900, meant a different approach as we were not allowed any social contact for many months. The safety of those who work for us, be they trustees, staff, third party workers, or volunteers they had to be protected at all times. Telephone calls were an obvious means of contact, social media channels too, in certain cases we also used facilities like Skype, Zoom or FaceTime where we could communicate face to face via the internet.

In a nutshell, deliveries to their door were up from 164 to 243, telephone calls up by just over a third to 2,720, and hours spent on social media channels increased by almost a third to 2,645 hrs. There was also a significant increase in call from those concerned about their own breathing conditions, or that of a relative, or friend - up from last year's total to just under 2,500. This also included us signposting callers to other organisations which could help with other issues such as housing, financial problems, loneliness, and mental health problems. Calls of the latter nature became more frequent towards the end of our year, especially, with cost-of-living crisis looming, caused in the main by Russia's invasion of Ukraine, another global issue which no doubt will cause many national issues in the coming months ahead.

As we enter a new financial year, we do so, secure in the knowledge that we're still standing as we approach our fortieth year - a truly significant achievement. The main objective of our work within the charity is to offer those who suffer from very debilitating respiratory conditions with a quality of life we all too often take for granted. The lockdowns caused by the pandemic has gone someway to many understanding the loneliness that a good number of our patients endure on a daily basis.

The photo below is one of our patients experiencing the enormous joy of simply being free to enjoy nature; not confined, or defined by her condition. Sincere thanks to all who make this possible for those we help.



Over many years of providing medical equipment we've helped various people to re-engage and enjoy life once again. Some after much time of being isolated by their respiratory illnesses and conditions. Of course, there are those who wanted to purely do things most of us consider mundane, like going to school, going to the shops or just regaining their independence.



This couple were able to take a holiday after many years without due to illness. NARA's provision of a portable nebuliser made it possible for them to travel.



After being supplied with a nebuliser this couple were able to celebrate their wedding anniversary.
Without NARA's help this would not have been possible



This lad needed help with a monitor from a very early age. With NARA's help he was able to start school along with his peers - something his parents never thought possible



Now a dad himself, we first helped the above man when he was just a schoolboy in need of a nebuliser. His dream was to become a singer in a band. Despite his condition his dream came true

#### THANK YOU FOR HELPING US HELP PEOPLE LIKE THEM





Sir David Amess - 1952-2021

On 15th October, like most, we were staggered to learn of the tragic, mindless and unnecessary loss of Sir David Amess, MP, violently assassinated whilst serving his constituents at his surgery in Southend-on-Sea. His passing tore into the hearts of many at NARA as during our infancy, whilst then Member of Parliament for Basildon, we were introduced to him. His advice, support and encouragement did much to assist us during those embryonic days when we were laying the foundations of our now long-established charity. Our photo shows him and his wife, Julia, at the Cafe Royal in London, in October 1987, where after just three years of operation we celebrated assisting 300 worried parents and their babies by providing them with necessary respiration monitors. Unfortunately, with the passage of time, and with the pressures of his work, both in government and local responsibilities, we lost touch with Sir David, but never forgot the kindness shown by a most generous man. To Julia, his children, Katie, Sarah and David Jnr, together with his extended family and friends, all at NARA offer our deepest condolences and sympathy.

### 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







## NARA - Annual Charity Accounts

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Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033





Caring for all generations

#### **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** Andrew Nottingham

Taxwright 65 Moss Street

Keith Banffshire AB55 5HE

Bankers Barclays Bank Plc

267 Wellingborough Road

Northampton NN1 4YD

I report on the accounts of the Trust for the year ended 30 April 2021 which are set out on pages 3 and 6

#### Respective Responsibilities of Trustees and Examiner

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

#### **Basis of Independent Examiner's Report**

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

#### **Independent Examiner's Statement**

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

- (1) which gives me reasonable cause to believe that in any material respect the requirements
  - to keep accounting records in accordance with section 41 of the Act: and
  - to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the Act have not been met or
- (2) to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

A W Nottingham FCCA

Taxwright 65 Moss Street Keith

Banffshire AB55 5HE Data

15/8/22

#### Statement of Financial Activities For the Year Ended 30 April 2022

		Unrestricted Funds		
	Notes	2022	2021	
Incoming Resources				
Donations from Grants, Trusts, Companies and Individuals	2	101,218	121,425	
Direct Charitable Expenditure				
Medical equipment care and support		94,507	100,691	
Other Expenditure				
Fundraising costs		1,728	2,040	
Management and Administration of the Charity	3	_11,230	10,647	
Total Expenditure Loss in value of monitors		107,465	113,378	
Expenditure after exceptional cost		8,325 115,790	113,378	
Net Movement in Funds for the Year		(14,572)	8,047	
Total Funds Brought Forward		42,311	34,264	
Total Funds Carried Forward		27,739	42,311	

There were no recognised gains or losses for 2022 other than those included in the Statement of Financial Activities.

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

### Balance Sheet as at 30 April 2022

	Notes	2022	<u>2021</u>
		£	£
Fixed Assets		25,019	33,344
Current Assets			
Cash at Bank and In Hand		3,140	9,453
Current Liabilities	5	(420)	_(486)
Total Assets less Current Liabilities		<u>27,739</u>	<u>42,311</u>
Capital			
Unrestricted Funds		<u>27.739</u>	<u>42.311</u>
Approved by the trustees on $\frac{29^{th}}{}$	aruary 23	and signed on their behalf	
Trustee		_	

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

#### **Notes to the Accounts**

#### For the Year Ended 30 April 2021

#### 1 Accounting Policies

#### 1.1 Basis of Preparation of Accounts

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

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

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

#### 1.2 Income

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

#### 1.3 Value Added Tax

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

#### 1.4 Fundraising Costs

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

#### 1.5 Management and Administration Expenditure

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

2.	Income	2022	<u>2021</u>		
		£	£		
	Net transfer from savings Donations Medical Contributions	100,738 480	2,000 118,635 <u>790</u>		
		101,218	121,425		
3.	Administration Expenditure				
	,	2022	<u>2021</u>		
		£	£		
	Office Rent and Services Administration Staff Independent Examination	6,778 4,032 420	6,081 4,080 <u>486</u>		
		11,230	10,647		
4.	Staff Costs				
	No remuneration was paid to trustees in the year, nor reimbursed. The staff costs were:	were any truste	es' expenses		
	Tollinguised. The stail costs were.	2022	2021		
		£	£		
	Wages and Salaries	4,032	4,080		
	The average weekly number of staff employed by the charity during the year was as follows:				
		2022	<u>2021</u>		
	Administrative	1	1		
5.	Current Liabilities	2022	2021		

Accrual

£

420

£

486