Newsletter

Edition 1, May 2025

PECTUS MATTERS

Welcome to the First Edition of the Pectus Matters Newsletter!

We are thrilled to bring you the very first edition of our Pectus Matters newsletter—a significant milestone for us as we officially launch the UK's first dedicated pectus charity. What began as a small group of passionate individuals determined to make a difference has grown into a national charity advocating for and supporting pectus patients across the UK. Our aim is to publish our newsletter quarterly, introducing you to clinicians that work in pectus clinics across the UK and also sharing insights and stories from our patients and trustees.
If you have any ideas on what you would like to see in a newsletter going forward, please do drop us an email at: info@pectusmatters.co.uk.

You will be receiving a copy of this newsletter because you have signed up to our charity as a friend of pectus matters. Membership is a key means of us raising money for our charity. Have you asked family members and friends if they would also like to sign up? For only £5 per month (minimum), you can have access to our newsletters as well as webinars. Please visit our website for more details at www.pectusmatters.co.uk

Quarterly News

Two of our Pectus Matters trustees recently attended a Pectus Symposium organised by St Bart's in London. The event brought together clinicians and representatives from not only hospitals around the UK but also worldwide to discuss best practice care for pectus patients. Ellie shared a Patient's perspective at the event. One of our key aims as a charity is to advocate on behalf of all of our patients.

Fundraising

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Over the next few editions, we would like to introduce you to our trustees and volunteers. Becky Blount is our trustee leading our fundraising strategy, She is delighted to share a little about herself and what our fundraising plans are for this year.

HI, I am Becky, I am a Trustee, co-founder and fundraising lead for Pectus Matters. My background is in healthcare and I currently split my time between working in operating theatres and supporting our family business with HR and Health & Safety. I am fast learning how to navigate the charity space and all fundraising related topics from legislation to engagement.

I have a passion for outdoor activities and raising money for charities. I have been taking on at least one event each year for various charities for around five years and now I am focusing that passion on how to raise funds and awareness for Pectus Matters. It has motivated me to attempt tasks such as the Yorkshire 3 Peaks and Get Caked.

The work we do at Pectus Matters is currently solely reliant on our fantastic fundraisers and the money we raise has facilitated the fundamental infrastructure we need in place to make our charity a safe and informative resource for all. This includes covering the cost of disclosure and barring checks (DBS) and the running of our website. We really need the might of our pectus community to support us in raising much needed funds to support our aims as a charity. Please do consider how you might be able to get involved.

Fundraising

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How can you help?

Visit our website at www.pectusmatters.co.uk and read all the support materials for how you can help us to raise vital funds for our charity work. These include:

1. Sign up to become a Friend of Pectus Matters

2. Take part in our Active April campaign to raise awareness and funds
- Make individual donations via our website or JustGiving

3. Sign up to Easyfundraising who will donate money from retailers from your online purchases

4. Recommend our charity to organisations, workplaces or schools when they plan charity events

5. Hold your own charity events such as a quiz night, car boot sale, raffle, sponsored walk, bike ride, or you could craft things to sell.

Take a look at some of our previous fundraising initiatives and events for inspiration, and please contact us at info@pectusmatters.co.uk to become a fundraiser or volunteer.

Clinician in Spotlight

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In each Newsletter, we plan to shine a spotlight on both clinicians and patients, by inviting them to answer a number of questions on their involvement and or/experience in pectus-related issues. For our very edition of this newsletter, we are thrilled to introduce you to Mr Aman Coonar who has played a pivotal role in getting treatment for pectus reinstated in NHS England. Given his influential role in the future direction of pectus care in England and the UK, we are dedicating this month's spotlight to him alone.

Meet Aman Coonar in Person

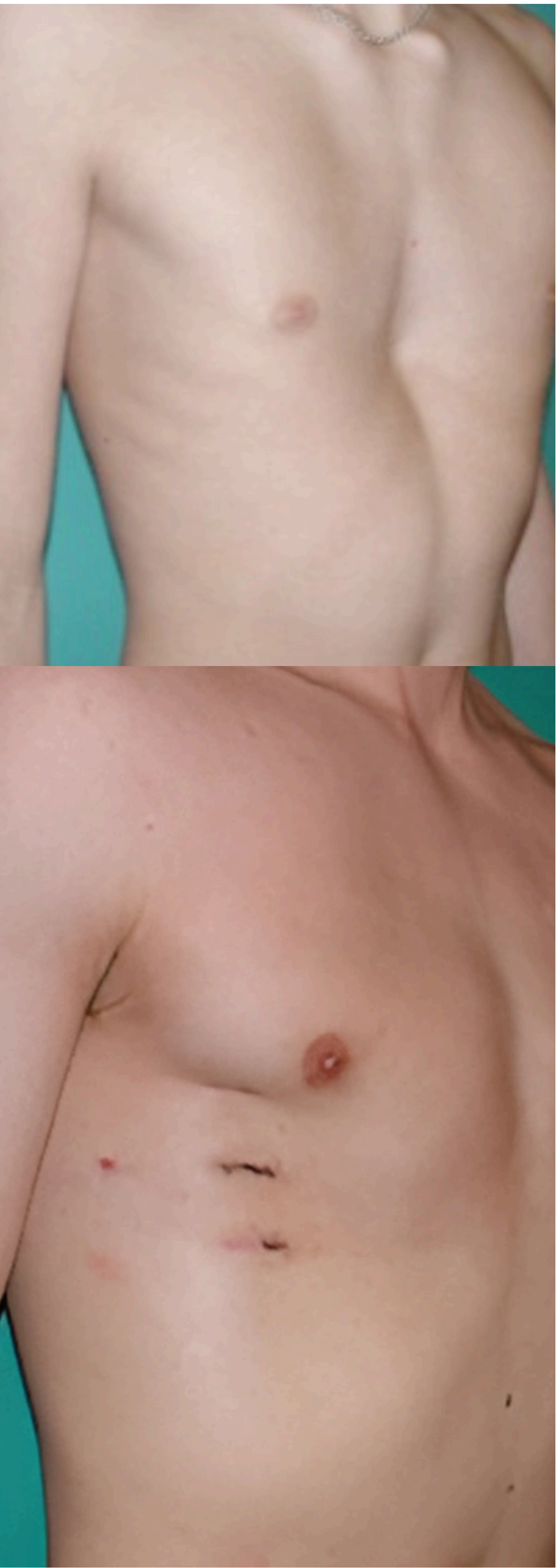
'Friends of Pectus' can join a Webinar with Aman on Tuesday, June 24th and hear about his vision for pectus treatment in UK, with Q&A

National Clinical Lead for Thoracic Surgery, NHS England

President, Society for Cardiothoracic Surgery in Great Britain and Ireland

Consultant Thoracic Surgeon, Royal Papworth Hospital, Cambridge, UK

Hi Aman, we are delighted you have agreed to be in the spotlight for our very first edition of the charity newsletter. Please could you let us know what is your role within the NHS and how does it influence care for pectus patients in the UK?



I am a thoracic (chest) surgeon in the NHS and hold national leadership positions that help shape how thoracic surgery is delivered across England. For pectus patients, I have been closely involved in designing and overseeing the recommissioned National Pectus Care Service. This work ensures that care is coordinated, evidence based, and available to patients wherever they live.

The NHS is a large and complex organisation, with limited resources and many competing priorities. To make progress, you need to plan ahead, build consensus, and present clear evidence that a service is needed and can deliver real benefit.

There are many meetings in the NHS, and most do not lead to meaningful change. I try to remain focused on action—on delivering improvements that matter to patients, not just talking. People and systems resist change!

I have also recently become President of the Society for Cardiothoracic Surgery of GB & Ireland. I hope that by putting these platforms together we clinicians can better design and deliver patient-centred care.

www.scts.org

What progress has been made in pectus care over the last two years?

The transformation has been remarkable. In 2020, routine pectus surgery on the NHS was effectively halted. Services collapsed, and many patients and families were left in distress.

Thanks to a determined campaign by patients, families, and clinicians—including the founding of this charity—we succeeded in getting a limited national service recommissioned in 2023. We moved quickly.

The national pectus multidisciplinary team (MDT) was launched within a week by Shyam Kolvekar at St Bartholomew's Hospital in London. He needs massive thanks. That took considerable courage, as funding was not yet finalised, and many practical barriers had to be overcome. He has since been joined by Henrietta Wilson as co-lead, and together it is doing really well.
Since the relaunch, the national service has achieved:

- Weekly national MDT meetings
- Clear referral pathways
- Shared clinical standards across centres
- Two new centres: one at James Cook Hospital in Middlesbrough (led by Joel Dunning) and the national children's pectus service at Alder Hey Hospital in Liverpool (led by Ram Dhannapuneni)
- More than 300 MDT case discussions
- A growing number of successful operations
- Support for the RESTORE research study

Patients are now being seen, supported, and treated in a far more joined up and consistent way—and it is making a real difference.

This progress has grown from a small group: myself, Shyam and Fiona Marley our brilliant ally from specialised commissioning and a lot of prayers.

Now the MDT has become a true expert forum, and its strength and continues to grow. We receive referrals from all round the country.

What is your ambition for the future of pectus care in England?

My ambition is that every person with a pectus condition should have:

1. Timely access to expert assessment
2. Personalised, safe, and effective care
3. Support throughout their journey, from diagnosis to recovery

Full access to NHS funded surgical and non-surgical treatments, including bracing for prominent chest conditions and the vacuum bell for sunken chest conditions

To achieve this, we need to build awareness among general practitioners and children's services, continue strengthening our specialist centres, and keep listening closely to patients and families. We also need to secure the right funding arrangements to support the service long term—and I am continuing to work on all of that.

What advice would you give to patients or parents newly diagnosed with a pectus condition?

Please do not panic. Pectus conditions are more common than many people realise, and support is increasingly available.

My advice would be:

- Seek accurate information from reliable sources
- Speak to your GP about a referral to a recognised centre
- Remember that you are not alone—there is a whole team here to support you
- Every patient's journey is different, and the best results come from working together with clinicians to make decisions that are right for you.
- For up-to-date information, please visit the Pectus Matters website.

www.pectusmatters.co.uk

Tell us something about you, Aman, that is not related to work?

Outside of surgery, I am a husband and father to six children. We love nature and try to spend as much time outdoors as possible. We love slow and simple travel and by that I mean 'living like a local', rather than sight-seeing. I like to read books related to my journeys. Not travel books as such, but about the lives of people where I am visiting. I value experiences over assets.

I am also deeply committed to improving work life balance in our profession. I do not want cardiothoracic surgery to be defined by the brutal hours that many of us experienced early in our careers. While we surgeons are generally very resilient and committed and sometimes love that work intensity; those extra hours come at the cost of family time and long-term health—and that is not fair or right.

I speak out against that culture and try to lead by example. I like to get my team home on time and know that if they are away they have been doing something fun. That does not mean I never send early morning emails or when needed do long operations BBC Two - Surgeons: At the Edge of Life, Series 3, Episode 2. I do so because the family are sleeping soundly (or recovering from a party), the house is quiet and I am at my most alert.

To meet Aman in person on a Q&A webinar on Pectus care in NHS England on Tuesday, June 24th, please join our charity as a Friend - details on our website: www.pectusmatters.co.uk

One last thing....

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One of our key objectives at Pectus Matters is to raise awareness for both the condition and the new treatment pathway with GPs.

The next time you visit your GP, please do take along a copy of this newsletter and hand it to them - or make them aware about Pectus Matters and direct them to our website where we have information on the new pectus treatment pathway. The more GPs that become familiar with pectus conditions across the UK, the better.