

SALIVARY GLAND CANCER UK

THE STORY SO FAR...





Letter from the Chair.

It's just over five years since I received an email from the Charities Commission advising me that 'Salivary Gland Cancer UK' was formally registered with them as a Charitable Incorporated Organisation.

After several months of discussions, drafting of documents and various pieces of admin, we were 'over the line' and had our very own charity number... We haven't looked back since.

We are incredibly proud of how far we have come in this short time and wanted to take this opportunity to show our gratitude and have a moment of reflection on what we have achieved so far.

I'd like to start with a personal thank you to everyone who has attended an event, discussion, or workshop, manned a stall, created, written, or filmed content or provided input and support to our community. Without you, we would not be here.

Many of you have been involved and supported us from the very beginning and we are humbled by the effort you make for us. I would also like to thank those who have taken on more formal responsibilities on the Board, all of whom are volunteers.

So what have we achieved in five years?

I can't count the number of times we have spoken at events, conferences and discussion groups about salivary gland cancers. All over the UK and internationally, we have reached out, met with collaborators, provided information and shared our knowledge and experience.

We're keen to share how our collaboration between patients and clinicians can move things forward for better patient outcomes, but we're equally keen to meet and learn from others with aligned goals and similar challenges.



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The work that Salivary Gland Cancer UK has been doing in the short time it has been going has been remarkable

- Jim, SGC Community Member

Interactions facilitate deeper understanding, allow for the sharing of best practice and foster the co-creation of new projects.

Supporting and developing a UK-wide referral mechanism for patients with salivary gland cancers and helping establish The Christie Hospital, Manchester as a hub, has been key to moving things forward.

The biobank at The Christie hosts samples of salivary gland cancers from all over the UK and from all the anatomical sites in which they are found. In a world of genomics, where full tumour profiling is available on the NHS and research into understanding the basic biologies of these cancers is beginning to accelerate – this is an incredibly important resource. The utility of this is demonstrated with several publications already coming from the team in Manchester.

A key milestone for us in 2023 was being in the position to put out our first grant call. Shortly following this in early 2024 was the inaugural UK Salivary Gland Cancer Research Working Group meeting. Pathologists, basic scientists, oncologists, surgeons, early career researchers, nurses and of course, patients came together ‘To identify the gaps in salivary gland cancer research and develop strategic priorities for this area of research’.

On a personal note, I felt it was humbling and quite moving to have so many people who cared about these cancers in the same room. I even dared to feel hopeful for the future.

We are a small organisation, but we have come a long way since we received our first ‘big cheque’ from Kaye Herbert in 2019. We have a lot of work to do, solid foundations on which we will continue to build, and the drive to keep moving forward. We look forward to having you with us on the next leg of our journey.

We would like to dedicate our 5-year annual report to those we have lost along the way.

With all the very best,

Emma Kinloch
Chair, Salivary Gland Cancer UK

Our Community.



>3,600 FOLLOWERS AND MEMBERS

Through our community gatherings, newsletters and social media presence, we have developed a community that's thousands strong.

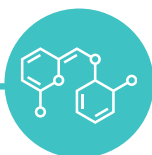
As well as patients and researchers, our membership includes clinicians of all types, from late-effects radiographers, pathologists, dentists and oncologists to head and neck surgeons.



>20 COUNTRIES REPRESENTED

From the Netherlands to Sweden, Indonesia to Brazil, and the US to Italy, our members come from all around the world.

Whether they're connecting with us at an international conference we're attending, joining us online at a community gathering or webinar, or speaking at our events in the UK, they are helping us build an international coalition.



>8 RARE SALIVARY GLAND CANCERS (AND COUNTING) REPRESENTED

When we began, our membership and work centered around adenoid cystic carcinoma—but not any more.

Our remit has grown to encompass acinic cell carcinoma, adenocarcinoma, basal cell adenocarcinoma, mucoepidermoid carcinoma, clear cell carcinoma, salivary duct cancer and secretory carcinoma.

And we won't stop until we've expanded to cover all salivary gland cancers.



“I went along to an SGC UK meeting and it was transformative. When you go into a room full of other cancer patients who have exactly the same tumour type as you, you don't have to explain anything. And that was very comforting.”

— Barry, SGC UK Member living with ACC

“Being at this SGC UK meeting today has been very powerful for me. I can't wait to get back to the lab and get going, because I can see the impact my research will have on so many lives.

Even though it's a rare cancer – in this room it affects 100% of the people.”

— Dr Vivian Petersen Wagner, Researcher

The 8 Aims of SGC UK.

Through patient-clinician collaboration, we have formulated our 8 core aims, which drive our work:

- 1** To build support and information networks to:
 - a. Bring together those living with salivary gland cancers, giving them access to the latest information on their disease, and mutual support networks.
 - b. Raise awareness of salivary gland cancers, their symptoms and treatments amongst the general public and the clinical community.
 - c. Bring together the patient, clinical and research communities to help drive forward research and improvements in treatments.
- 2** Support advances in the understanding of the experience of living with and beyond these cancers, and the development of interventions to improve this experience.
- 3** Improve the rate of early diagnosis for salivary gland cancers.
- 4** Optimise the pathways to diagnosis.
- 5** Support the development of standardised guidelines for the management and surveillance of individual salivary gland cancers.
- 6** Understand the effectiveness of different types of radiotherapy for specific salivary gland cancers.
- 7** Support the development of surgical and radiotherapy treatments to deliver improved survivorship and quality-of-life post-treatment for salivary gland cancer patients.
- 8** Support the development of standard drug treatments for salivary gland cancers to improve life expectancy and survivorship by:
 - a. Supporting basic research into the biology of individual salivary gland cancers.
 - b. Supporting translational research that turns this basic knowledge into effective treatments.
 - c. Developing and pushing forward drug trials to test the effectiveness of both existing drugs, and those specifically developed to target a particular salivary gland cancer.



Research Working Group Activities.

Following the closure of the National Cancer Research Institute (NCRI), this working group was tasked 'to identify the gaps in Salivary Gland Cancer Research and develop strategic priorities for this area of research'.

Our inaugural meeting in March 2024 was attended by clinicians, researchers and patient advocates from all around the UK and beyond. Cross-border collaborations across all four nations of the UK, and internationally, are absolutely key to driving forward research into these cancers.

The group met, shared knowledge and expertise, and identified a list of research questions (RQ). Following a subsequent prioritisation exercise, we are now delighted to have four active workstreams addressing the top four ranked RQ's. In addition, several ad hoc projects are underway.

RQ 1. Address the utility of Guidelines for Salivary Gland Cancers (SGC)

RQ 2. Assess the variation in histopathology reporting for Salivary Gland Cancers (SGC)

RQ 3. Standardise the decision-making processes for patients who have technically operable, Salivary Gland Cancer (SGC), where the surgery carries high morbidity

RQ 4. Improve the diagnostic pathway for Salivary Gland Cancer (SGC) patients



Our Grants.

In 2023 SGC UK put out its first call for grant funding and subsequently made awards to two key projects. Our ever-expanding network of clinicians and patients has played a key role in this, raising awareness of our work, and funds for it to grow and expand. Thank you.

THE TEAM MOLLY GRANT: OPTIMISING THE PATHWAYS TO DIAGNOSIS

A consistent challenge raised by our patient community is that the pathway to diagnosis from the point of first engaging with any healthcare professional is difficult. Salivary gland cancers can present in many different ways and are rarely seen by clinicians, which means symptoms are often misdiagnosed and diagnosis can be slow.

To address this, SGC UK awarded funds to Dr Rack at The Christie Hospital in Manchester to map the pathways to diagnosis, develop guidance for front-line medical services to support the diagnosis of salivary gland cancers, and to have that guidance approved by NICE (National Institute for Health and Care Excellence) and the NHS.

A SALIVARY GLAND REGISTRY

The second grant supported the rollout of a UK-wide salivary gland cancer surgical registry. This will allow for the collation of data and patient-reported outcomes. The registry will be vital in understanding the natural history of salivary gland tumours, generating future research hypotheses, assessing and informing clinicians and patients about the clinical outcomes with current treatments, providing faster diagnosis and designing care pathways.

We are delighted to have leveraged our international work and contacts to connect the UK team with colleagues in Europe who are building an EU based registry for salivary gland cancers. Sharing and collaboration like this is vital to improve outcomes for salivary gland patients.



Bringing people with SGC together.

Our hybrid (in-person/virtual) meetings are semi-annual and we provide support for attendees with travel bursaries for patients and their carers where needed. We divide the day between more 'person-centered' discussions in the morning, sharing our experiences and knowledge and hearing from those supporting Living with and Beyond Cancer (LWBC).

Afternoons are research and project-focused with expert speakers. The hybrid structure of our events has facilitated strong engagement from our community across the country and internationally.

KEEPING EVERYONE UP-TO-DATE

We provide regular communication and newsletters to the network. We continue to produce our video series, releasing recordings of presentations at our hybrid meetings to ensure we reach as many people as possible. We have a series of patient stories on our YouTube channel which are regularly reported as 'inspirational' by members.

OUR PATIENT AND PUBLIC INVOLVEMENT (PPI) WORK

We have involved our patients and carer members at every step of the way in our SGC UK work. Initially, we co-created our 8 aims which underpin all our work, and over the years we have worked with our members on key projects of value to improve outcomes and further research into salivary gland cancers.

We were delighted to work with industry experts to produce genomics leaflets to explain in layman terms what genomics is, how it can help patients and how our community can access genomic profiling of their tumour.

Over the years our Patient and Public Involvement (PPI) work has continued to grow and develop. We are regularly called upon to input into the design of research studies, provide feedback on trial protocols, help researchers develop lay summaries of their work and of course, bring the perspective of those with lived experiences to discussions.



Raising awareness.

THE CLINICAL COMMUNITY

As a team, we are present at as many relevant events as we can be. We have spoken at conferences, meetings, workshops, discussion groups, seminars and basically whenever we get a chance!

We have manned stalls, sat on panels, co-authored papers and produced posters because spreading the word across the UK and beyond is key to what we want to achieve.

Events provide an excellent opportunity to expand networks of researchers, clinicians and patient advocates. They also provide the opportunity to meet key members of the clinical and patient communities in person. Often the opportunity to ask publicly 'What about salivary gland cancers?' is presented and we always grasp it with both hands!

Some highlights include posters at large international conferences such as the American Society of Clinical Oncology (ASCO), speaking at the European Society for Medical Oncology (ESMO) Rare conference, a panel discussion for GP Pulse and manning stalls at several conferences and events across the UK - always busy, challenging and fun.

PUBLIC AWARENESS

The most significant event in raising public awareness of salivary gland cancers took place in September 2023, when over 130 of our supporters donned a Salivary Gland Cancer UK running vest and pounded the streets of Sheffield to complete a 10k run.

This was a hugely impactful awareness-building and fundraising event. Thank you, again, to #TeamMolly who organised it.

The SGC UK Board.



EMMA KINLOCH

MA (HONS) OXON, MSC

CO-FOUNDER AND CHAIR

Emma graduated from Oxford with a degree in Experimental Psychology and went on to have a successful career in finance for over 20 years, working across Asia and Europe.

She joined the National Cancer Research Institute's (NCRI) Head and Neck Group in 2015, was appointed Chair of the NCRI Consumer Forum in 2019, and later became co-chair of the Salivary Gland Cancer workstream. She co-founded the SGC UK charity in 2019.

Emma is a non-Executive Director of the Adenoid Cystic Carcinoma Research Foundation, a member of the Experimental Cancer Medicine Centre Strategy Board, and acts as an advisor to the EURACAN Head and Neck domain. She is currently pursuing a PhD in Occupational Health Psychology.



DR ROB METCALF

MB CHB PHD MRCP

CO-FOUNDER

Rob is a consultant head and neck cancer medical oncologist and clinician scientist. His clinical and research focus is on salivary gland cancer, and he sees patients from across the UK. He runs clinical trials and performs translational studies at The Christie NHS Foundation Trust, one of Europe's largest cancer hospitals, and The University of Manchester.

To inform the development of the next generation of clinical trials, he is developing a laboratory research program within the Cancer Research UK Manchester Institute, with an initial focus on adenoid cystic carcinoma biology. His research examines genomic profiles in salivary gland tumour samples to identify alterations that can be targeted by drug therapies, and to develop an understanding of how changes at the level of the gene/protein result in tumour growth and metastasis.



SHANE DRAPER

ACCA

CHIEF FINANCIAL OFFICER

Shane is a qualified Chartered Certified Accountant and currently serves as Chief Financial Officer at SGC UK. She began her corporate career in audit at Ernst & Young, later joining Goldman Sachs Asset Management, where she held various roles in operations and client relationship management, before becoming Chief Operating Officer and Chief of Staff for the firm's European entity.



KEMI OLAIYA

CMGR MCFI

TREASURER

With over 20 years of experience in financial services, Kemi has worked across a range of specialisations and locations. She has been an active member of charity committees within the workplace and an enthusiastic fundraiser - including a 500-kilometre sponsored cycling ride in Kenya. Kemi has worked with well-known charities including Ambitious about Autism, Demelza House, and Smart Works. SGC UK holds a special place in her heart.

Our Volunteers.

A big thank-you goes to our wonderful volunteers who have done so much to help drive our work forward.

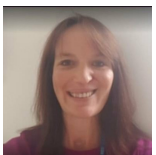
People like Sammy and Jamie, who have manned (and womaned) our stalls at key events and conferences. Sarah, Jo and Rosanna, who have helped out with our comms and Barry, Ian and Pauline who provided invaluable patient insights as we worked to develop our 8 strategic aims.

We couldn't have got here without you!



ROSANNA HUNTER

Rosanna has been volunteering with us since the charity was founded in 2019. As a professional copywriter, she's supported the development of our marketing and communications, including setting up our website, writing digital and print content, and assisting with video production. She's also occasionally to be found spreading the word on one of our stalls.



SAMMY ROKOSZYNSKI

Sammy was diagnosed with adenoid cystic carcinoma in March 2016 and has been attending SGC UK's patient and carer gatherings since 2020. More recently, Sammy has begun volunteering and representing SGC UK at regional events. She is also a member of the SGC Research Working Group. With 25 years of experience in the NHS as a registered nurse and a specialist in improvement and change, Sammy brings both personal and professional expertise to the charity.



JAMIE MACDONNELL

Jamie is an active member of our community and has worked on our genomics leaflets, regularly attends our gatherings and most recently manned an SGC UK stall. He was a firefighter in London for 30 years before being diagnosed with adenoid cystic carcinoma in 2019.

He attended the Ladbroke Grove Train Crash, 7/7 Bombings and the Grenfell Tower Fire. He is a true believer in a positive mental attitude. 'Through my profession, I've seen people in their worst of times and that's what has been part of the foundation of my attitude. Every day is a bonus, keep moving forward'.

A huge **THANK YOU** to all our supporters, who've baked, swum, run and walked their way to raising vital funds for SGC UK.

Salivary Gland Cancer UK

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