

Kidney Cancer Support Network (also known as KCSN)

Trustees Report for the year ended 31st October 2018

The Trustees present their report with the financial statement for the year ended 31st October 2018. In preparing this report, the Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "accounting and reporting by charities" issued in March 2005.

Registered charity number: 1164238

Status: Charitable Incorporated Organisation (CIO) Incorporated 3 November 2015

Principal and registered address:

Kidney Cancer Support Network,

The Office, The Bungalow,

West Cliff, Porthtowan

Cornwall TR4 8AE

Trustees

- I. Mr Andy Thomas – Chair
- II. Dr James Larkin
- III. Prof Charles Swanton
- IV. Ms Debbie Victor
- V. Mr Jonathon Pym

Structure, governance and management

Kidney Cancer Support Network (KCSN) has existed as a voluntary support organisation since 2006. It was registered as a charitable incorporated organisation (CIO) on the 3 November 2015 and the charity is managed according to its governing documents dated 3 November 2015.

Where there is a requirement for new Trustees, they will be identified and appointed by the current Trustees. The KCSN management team is responsible for the induction of any new Trustees, and this will involve a briefing about Trustee responsibilities, the governing document, and the adopted operating policies and procedures of the charity. All Trustees provide their services to the charity for free.

The Trustees delegate day-to-day responsibility for the running of the charity to the KCSN management team who are accountable to the Trustees and report to the Trustees throughout the year and formally at regular Trustee meetings.

The Trustees have a duty to identify and review all risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. The Trustees regularly review the risks that the charity may face and the Trustees will continue to monitor the risks associated with its activities and continue to be vigilant as to other risks that might be associated with a charity providing support services to those affected by kidney cancer.

The Trustees have agreed and adopted a series of operating policies to ensure the charity runs smoothly and complies with all charity commission requirements and legal responsibilities. These operating policies are currently reviewed on an annual basis and are available by written request to the KCSN management team or via the KCSN website.

The Trustees declare as part of this annual return that there are no serious incidents or other matters that Trustees should have reported to the Charity Commission.

Objectives and activities

The stated objectives of the charity are to promote and protect the physical and mental health of patients with kidney cancer in the United Kingdom through the provision of information, support, education and practical advice to patients, their families and their carers, and to raise awareness and advance the education of the public in all matters relating to kidney cancer.

The Trustees meet a minimum of twice a year, to discuss, agree and record funding priorities, charitable activities, strategy and operating policies including risk management. Project meetings are held throughout the year as required or as requested by the Trustees or management team

Public benefit

The Trustees confirm that they have referred to the guidance provided by the charity commission's general guidance and advice on public benefit. In planning all activities including financial policies, the trustees confirm they have complied with the duty in section 17(5) of the 2011 Charities Act and the Trustees are satisfied that all charitable activities during the year are for the benefit of the public.

Achievements and performance

KCSN is a cancer support organisation that seeks to educate and inform the public in all aspects of kidney cancer. KCSN is the only patient-and carer-led kidney cancer charity in the UK and this gives our charity a unique perspective and understanding of the needs of kidney cancer patients, their carers, families and members of the public who wish to educate themselves about kidney cancer.

KCSN seeks to raise awareness of kidney cancer with the public and to improve the lives of kidney cancer patients, carers and family members of people affected by kidney cancer by providing advocacy, information, general resources, emotional and practical support.

The charity has continued to build upon the work carried out in the two successful previous years. During our third full year as a charity ending 31 October 2018, the charity has been very busy and engaged in a number of successful charitable activities to meet the objectives set by the Trustees.

- The respect for our kidney cancer patient advocacy work has increased again this year and we have provided an expert patient perspective at various meetings, advisory boards and conferences organised by the National Cancer Research Institute, International Kidney Cancer Coalition (IKCC), National Health Service (NHS), pharmaceutical industry, National Institute for Health and Care Excellence (NICE) and various patient involvement organisations i.e., Cancer 52, All Party Parliamentary Group on Cancer (APPGC), Patients Involved in NICE (PIN), Independent Cancer Patient Voice (ICPV) etc. This advocacy on behalf of the kidney cancer community is a vital part of our work and KCSN is recognised nationally and internationally as a genuine patient led charity providing a strong and patient-centred voice.

We continue to campaign publicly for meaningful patient involvement in all aspects of research, diagnosis, care, treatment and survivorship

- We have continued our investment in our patient-focussed, patient-friendly website www.kcsn.org.uk and the ongoing updating of clear, accurate and up-to-date information about kidney cancer in a patient friendly and easily understood language
- We continue to work with the National Cancer Research Institute(www.ncri.org.uk), to improve geographical spread and recruitment and retention of patients into renal cancer clinical trials around the UK and to further research towards a cure for kidney cancer. Two volunteer members of the KCSN now sit as expert patient representatives on the NCRI Renal Cancer and Bladder Cancer Clinical Studies Group which is a prestigious group of leading renal cancer clinicians and patient advocates.
- We have made available patient information leaflets which have been distributed by KCSN members throughout the UK to hospitals and GP surgeries providing contact details for the KCSN to enable patients to come together to share experiences, exchange information and support each other.
- Provision of the only “peer to peer” kidney cancer support telephone helpline in the UK operated by patients themselves to provide a friendly yet knowledgeable point of contact for patients and carers to discuss their concerns in an open, impartial and non-judgemental way. Our aim is to provide patients with an individual and personal service; providing quality peer-reviewed resources and personal advocacy as required
- We have continued to invest in our unique comprehensive kidney cancer clinical trials database on our website which is used by kidney cancer patients, clinicians and nurses. Our clinical trials database is a fully functional searchable database written in patient-friendly language and complemented with a full glossary and a range of patient educational resources, both written and video format. We offer support and work alongside individual patients to search and help identify specific clinical trials and ensure that patients have a full understanding of any clinical trials which may be suitable for them
- We have added to the first ever library of “patient to patient” help sheets written directly by patients and carers to share their experiences, insights, tips and knowledge gained from their direct and unique understanding of what it is like to live with kidney cancer
- Our unique KCSN private “peer to peer” online discussion forum now has an active membership of over 1100 UK-based kidney cancer patients and carers. This 24/7 support service is managed by a volunteer admin team of expert patients and advocates. This very busy and welcoming forum offers information, shared patient experiences, patient, carer and family support and is now regularly recording over 6000 patient interactions every month covering all aspects of kidney cancer diagnosis, treatment, survivorship and beyond.
- KCSN is a founding member of the International Kidney Cancer Coalition (IKCC) and Rose Woodward is a volunteer Director of the IKCC Board. Through this affiliation with IKCC, the KCSN works closely with other patient advocacy groups around the world to promote global awareness and better treatments for all kidney cancer patients. As a member of the IKCC

Board, the KCSN has been called upon to review materials for the international kidney cancer community, participate and present international conferences, take part in international advisory boards and participate in medical conferences and symposia to provide a patient perspective.

- KCSN participated in the International World Kidney Cancer Day that took place in June 2018 leading the UK campaign with events around the country and articles and interviews in the regional and national media to raise awareness of kidney cancer
- We publish a professionally written quarterly KCSN kidney cancer newsletter which updates our community of patient, carers, clinicians, nurses and Healthcare Professionals with the latest kidney cancer research and reviews, interviews, patient perspectives into current news items, opportunities for patient involvement and fundraising and awareness raising activities.
- During the year we have arranged and facilitated regional social events around the UK for people affected by kidney cancer to come together to share their experiences and information, provide mutual support and build friendships to help bolster confidence and lessen loneliness faced by patients with a less common cancer
- We have continued our clear mission to provide evidence based, well researched, strong but independent patient submissions to health technology appraisals (HTA) related to kidney cancer and the care of kidney cancer patients. We have provided an expert patient statements at HTA committee meetings of various regulatory bodies, e.g. NICE and the Scottish Medicines Consortium (SMC)
- Our bespoke Patient Registry continues to record unique and previously unavailable real-world information directly from patients and carers. The outputs from this registry can be used to highlight variations in care and outcomes across the UK and to inform HTA submissions thus helping to improve the lives of kidney cancer patients wherever they live in the UK
- KCSN wrote and published a comprehensive revision to the first edition of the global Decision Aid booklet for patients with advanced/metastatic renal cell carcinoma to facilitate shared decision-making in hospitals/clinics around the world


Financial review

During our third year as a formal charity, KCSN received an income of £ 96,253. The charity holds its funds in a bank account with the ethically managed Co-operative Bank. The management team, together with a part-time book-keeper, manage receipts and payments with oversight from the Trustees. The charitable income is provided through donations and fundraising by patients and supporters, supplemented by industry grants and charitable donations. The management team donate all advocacy fees paid to them for their expert patient work directly to the charity.

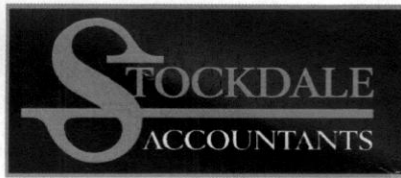
At the end of a successful third year operating as a formal charity, KCSN go forward into 2019 full of ideas about how we can make a difference to the lives of patients, carers and their families who are facing the hard reality of living with kidney cancer.

This year we have reached out and supported more patients and families than ever before, whilst at the same time keeping our overheads to an absolute minimum. The charity has maintained its focus on practical patient services; providing patients with excellent resources and emotional support. Combined with our exceptional advocacy work undertaken at an individual patient and a public level, we feel we have achieved the charity aims and objectives.

The Trustees and the management team would like to express their sincere thanks and appreciation to all the volunteers and supporters who have helped to establish the KCSN as a well-respected and thriving charity. Without our patients and volunteers, we would not be able to do what we do: we know that KCSN is making a huge difference to the lives of kidney cancer patients across the UK.

Signed  Dated 1 Aug 2019

Mr Andy Thomas – Chair of Trustees, Kidney Cancer Support Network



Kidney Cancer Support Network

Charity number: 1164238

Unaudited Income and Expenditure Account

For the Year Ended 31st October 2018

Kidney Cancer Support Network

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Kidney Cancer Support Network

General Information

For the Year Ended 31st October 2018

Address: The Bungalow
Westcliff
Porthtowan
Truro
Cornwall
TR4 8AE

Accountants: Stockdale Accountants Ltd
St. Inguner Offices
Lanivet
Cornwall
PL30 5HS

Financial Statements
For the Year Ending 31st October 2018

Accountants Report to
Kidney Cancer Support Network

In accordance with instructions given to us we have prepared without carrying out an audit the annexed Trading and Profit and Loss Account from the accounting records of Kidney Cancer Support Network and from information and explanations supplied to us.

Stockdale Accountants Ltd
St Inguner Offices
Lanivet
Bodmin
Cornwall
PL30 5SH

Date:

H. Hall 12/8/19

Client Approval Certificate

I approve the Profit and Loss Account and confirm that I have made available all relevant records and information for its preparation.



Kidney Cancer Support Network

Date:

12th August 2019.

Kidney Cancer Support Network
Income and Expense Account
For the Year Ended 31st October 2018

	2018 £	2017 £
Receipts		
Patient donations	35,162	23,055
Charitable donations and grants	45,544	59,000
Advocacy fees	15,547	4,585
	<hr/> 96,253	<hr/> 86,640
Payments		
Patient support	14,533	16,554
Advocacy and medical relations	11,576	13,485
Website and maintenance	14,912	17,794
Office and administration	12,945	11,955
Accountancy	100	100
	<hr/> 54,066	<hr/> 59,888
Surplus of receipts over payments	<hr/> 42,187	<hr/> 26,752

The charity held £77,477 at the bank as at 31st October 2018 (£37,762 in 2017).

The charity holds fixed assets of £1,216, current assets of £10,000 and has liabilities of £8,745.

The work done by the charity is held accountable to the five trustees.



St Inguner Offices – Lanivet – Cornwall – PL30 5HS

Telephone: 01208 831777 Email: office@stockdaleaccountants.com

Independent Examiners Report to The Kidney Cancer Support Network (1164238)

I report on the accounts for the year ended 31st October 2018

Respective responsibilities of the Trustees and the Independent Examiner

The charity's trustees are responsible for the preparation of the accounts in accordance with the requirement of the Charities Act 2011.

The charity's trustees consider that an audit is not required for this year under Section 144 of the Charities Act 2011 and that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under Section 145 of the 2011 Act
- To follow the procedures laid down in the General Directions given by the Charity Commissioners Section 145 (5)
- (b) of the 2011 Act: and
- To state whether particular matters have come to my attention.

Basis of Independent Examiners Statement

My examination was carried out in accordance with the General Directions given by the Charity Commission.

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 the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.



St Inguner Offices – Lanivet – Cornwall – PL30 5HS

Telephone: 01208 831777 Email: office@stockdaleaccountants.com

Independent Examiners Statement

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with Section 130 of the Charities Act; or
- the accounts do not accord with the accounting records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Mrs H Hall, MAAT
Stockdale Accountants Ltd
St Inguner offices
Lanivet
Bodmin
Cornwall
PL30 5HS

A handwritten signature in black ink, appearing to read 'H Hall', is written over the printed name.

Date: 12th August 2019