

# **ICUsteps Annual Report 1 February 2020 – 31 January 2021**

**Registered charity no:** 1169162

**Registered address:** ICUsteps, Kemp House, 152 City Road, London EC1V 2NX

## **Our aims are to:**

- support patients and relatives affected by critical illness;
- promote recognition of the physical and psychological consequences of critical illness through education of the medical profession and the general public
- encourage research into treatment and the prevention of these issues.

We fulfil our aims through voluntary positions. These are Chief Executive, Chair, Treasurer, Secretary, Research Manager, Lead Clinician, Fund Raising Manager, Information Manager and our other trustees.

Our work is overseen by the Board of Trustees. We have twelve trustees representing patients, relatives and intensive care healthcare professionals.

ICUsteps continues to promote patient and relative support after intensive care treatment. We have done this in line with our strategic plan in the following ways:

## **COVID-19 pandemic**

In 2020 and into 2021, intensive care units (ICU) across the UK and beyond were faced with an unprecedented challenge due to the COVID-19 pandemic. Although not all patients required admission to ICU, a significant proportion required invasive and non-invasive ventilation. ICUs were nearly overwhelmed by numbers.

Hospitals and clinicians were able to flex their ICU capacity to ensure patients were not denied admission, however the incredible sense of uncertainty increased fears that we could reach that point. Relatives and carers were told to stay away to reduce the risks of spreading the infection, which meant patients relied on the care and support of staff alone. Sadly, many patients died without their families by their sides, increasing the trauma for all involved. For ICU survivors, COVID-19 led in many cases to higher levels of delirium and a difficult recovery through “long COVID”. The psychological and physical wellbeing of expert staff was tested hard during the year.

However, there were some positives. A light was shone on the role of intensive care and traditional and social media highlighted issues ICUsteps has campaigned about since it was founded in 2005. As demonstrated in the past year, ICU patients need professional and peer support and information throughout their recovery pathway. So do their relatives and carers. The ICU journey does not end with discharge to the ward: a life saved is not enough. As a country, we need to ensure people are enabled back to a life lived to the best of its potential through rehabilitation and psychological support. That is how ICUsteps can help.

## Support

Since starting as a small local group in Milton Keynes, ICUsteps has developed a strong reputation in the critical care community. We enable local intensive care support groups to benefit from the name recognition and reputation we've established by applying to be affiliates of ICUsteps. As affiliates, groups benefit from being part of a network of likeminded peers and healthcare professionals working towards common aims with a recognisable brand. They can also contribute to our role as a national intensive care patient organisation by helping us to speak with a louder, more representative critical care patient voice.

There are 22 affiliated groups in England, Scotland, Wales, Northern Ireland and Ireland. Sadly, COVID-19 brought many challenges for these groups. Face-to-face peer support meetings were postponed, however, some groups successfully transitioned over time to the virtual world. Zoom proved to be a great way for patients, relatives and clinical professionals to continue to come together and support each other after critical illness. As a charity and affiliate groups, we have learned how to coach attendees how e.g. to use the gallery view and to 'unmute', however, the core advice and support on how to pace recovery and to deal with flashbacks and unexpected hair-loss remained the same. Groups in Brighton, Edinburgh, Gateshead, Chester, Bury St Edmonds, Dublin, Newport South Wales and Milton Keynes continue to meet online and ICUsteps plans to issue guidance on how to safely restart face-to-face meetings. We are conscious though of the toll of the pandemic on the clinical professionals that support the groups, which meant some groups were suspended for periods of time.

During the pandemic, we started ICUsteps Zoom Q&A sessions as an attempt to bridge the information gap for patients after ICU. We held sessions with our trustees, clinical specialists in critical care, and patients who had themselves been critically ill. We covered a range of topics around recovery from critical illness, including delirium, advice on flashbacks, weight loss and nutrition, exercises and physiotherapy. We had a steep learning curve as we hosted live Zoom sessions, which are available on the ICUsteps' YouTube channel, and which act as a useful source of information for healthcare staff.

We continue to have national and international contacts seeking our expertise and knowledge on how to set up local groups. We now have a selection of information that can be downloaded to help with the process.

ICUsteps continues to play a prominent and significant part in the development of guidance and services for critically ill patients by working with many organisations to represent the patient voice.

We continue to work on development of an ICU Patient Diary app. When completed, the app will be available on iOS and Android platforms to leverage the facilities of mobile devices to record a diary for critically ill patients that will later help them fill in the gaps of the time they cannot remember, to help them come to terms with their experiences. The app is being developed in consultation with healthcare professionals and the International Diary Network.

## Online Community

Our online community at <https://icusteps.healthunlocked.com> has continued to grow in the last year with 5,284 members a rise of 33.4%. Page view increased by 76% to 215,703 compared with the previous year and an all-time content increased by 88% to 16,246 posts from healthcare professionals, patients & relatives offering both support and advice to those that most need reassurance from people that understand what they have been through or are going through.

## Information

It has been another busy year for activity related to patient and relative information. We published 4 new information sheets – 3 relating to nutrition at different stages of critical illness and ‘About the ICU’ an information sheet for children unable to visit ICU.

We continue to receive requests from around the world to use our information. We give permission after receiving confirmation that patients and relatives will not have to pay to have the information.

We offer printed copies of two of our information booklets to UK hospitals – ‘Intensive Care: a guide for patients and relatives’ and ‘Visiting the Intensive Care Unit’ an activity book provided to children who have a special person in Intensive Care. There is a small charge per booklet for hospitals buying the guide and the children’s booklet is sent to UK hospitals free. For the period covered by this annual report, we received orders for the guide from 43 hospitals totalling 13375 booklets. We also received funding from

- the Moondance Foundation to supply 3750 free copies of the guide to 15 hospitals in Wales and
- the National Lottery Coronavirus Community Support Fund to supply 107,750 free copies of the guide to 221 hospitals in England.

We were delighted that our children’s booklet ‘Visiting the ICU’ was included as a best practice case study in the Patient Information Forum’s guide <https://pifonline.org.uk/resources/publications/2020-guide-to-producing-health-information-for-children-and-young-people/>

Website traffic changed over the past year with page views increasing by 7.9% to 117,568 compared with 109,001 in the previous year. At the same time however, visitor numbers and visits have both decreased by 11.3% to 45,045 and 15.1% to 34,511 respectively. This would indicate that while fewer visitors came to the site, those who did were more engaged, which is confirmed by the average session duration increasing by 23.3% and the bounce rate reducing by 13.2%.

## Research

Research has continued to be a key area of activity this year, with ICUsteps involvement being requested in numerous projects.

ICUsteps is a partner in a successful research bid to the European Union under the Erasmus stream. The project has now identified competencies for advanced nurses in Critical Care.

In December 2020 our Research manager presented an abstract at the European Society of Intensive Care Medicine (ESICM) Congress in Berlin on behalf of ICUsteps. This covered research undertaken to examine ICU patients and relatives perception of the advanced nursing competencies. ICUsteps undertook three focus groups, one in Milton Keynes, one in Edinburgh and one in Athens, Greece, with ex-ICU patients and their families to ensure that the nursing competencies reflected the needs of service users. The results were presented at the virtual ESICM Annual Congress in December 2020. They will be submitted for publication in the journal Intensive and Critical Care Nursing in due course.

### ***New support group “ICUsteps the next step”***

Our research manager volunteered to help with the zoom support group meetings organised by ICUsteps Chester. One of the patients attending the meetings contacted our research manager with another patient to discuss the need to support for ICU patients who are looking to put their experiences behind them and no longer identify themselves as ex-patients. Following an online discussion a new support group was established using positive psychology to facilitate post traumatic growth. This has been meeting monthly.

### ***Representation at the National Critical Care Research Conference***

ICUsteps had a stall at this meeting in Edinburgh in June 2020. Unfortunately this meeting was cancelled due to Covid.

Our research manager will attend the virtual conference in June 2021 and emphasise the help ICUsteps can offer researchers. There will be a stall at the 2022 meeting in Edinburgh.

### ***Information group***

The information group is a small group of ex-ICU patients and relatives who will comment on Plain English summaries for researchers. They usually respond with comments within 3 days. Over 2020, the group commented on 23 patient information sheets and lay summaries.

There have been 26 requests for help with research studies by researchers over 2020, with a broad range of topics. Six studies asked us to canvas the ICUsteps research volunteers to take part in the research.

### ***Co-applications on research studies***

ICUsteps was asked to be co-applicants on two research projects. REGAIN trialling virtual exercises for hospitalised COVID patients and PIM-COVID, looking at COVID-19 ICU patients experience of recovery.

## **Awareness and Collaborations**

Raising awareness of the impact and consequences of critical illness continue to be a priority for our organisation.

We have collaborated on many projects, including the HEE Capital Nurse critical care education development (for registered nurses and allied health professionals) and the ICS rapid guideline group to support re-introduction of face-to-face visiting and ongoing support for virtual visiting by family members as we emerge from the COVID-19 pandemic.

ICUsteps has been represented at national level by attending meetings for the CC3N (Critical Care National Network Nurse Leads), CCLF (Critical Care Leadership Forum), ICS patient and relative committee (Intensive Care Society).

## **Fundraising**

ICUsteps has continued to receive generous donations from individuals, small groups and corporate companies.

We were fortunate to receive £2000 from Schroder Charity Trust in November 2020 as an unrestricted grant.

The charity trustees have complied with their duty to have due regard to the guidance on public benefit published by the Commission in exercising their powers or duties.

## **Trustees for financial year 1<sup>st</sup> February 2020 - 31<sup>st</sup> January 2021**

Peter Gibb - Chief Executive

Mo Peskett - Chair

Bill Ridley – Secretary ( resigned 6/2/2020 )

Andrew Davis – Secretary ( appointed 6/9/2020 )

Phil Smith - Treasurer

Catherine White - Information Manager

Dr Christina Jones - Research Manager

Dr Kate Regan Lead Clinician

Anthony Vollmer

Helen Ashley-Taylor Fundraising Manager

Dr Pamela Page (appointed 6 September 2020)

Tracey Rich ( resigned 12/5/2020 )

Bryan Hislop (appointed 6 September 2020)

Dr Julie Highfield (appointed 6 September 2020)

This annual report was approved by the Trustees on 3<sup>rd</sup> October 2021 and signed on their behalf by:

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Mo Peskett  
Chair

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Andrew Davis  
Secretary

ICUSTEPS

Receipts and payments accounts

CC16a

For the period  
from

01/02/2020

To

31/01/2021

Section A Receipts and payments

|                                                       | Unrestricted funds<br>to the nearest £ | Restricted funds<br>to the nearest £ | Endowment funds<br>to the nearest £ | Total funds<br>to the nearest £ | Last year<br>to the nearest £ |
|-------------------------------------------------------|----------------------------------------|--------------------------------------|-------------------------------------|---------------------------------|-------------------------------|
| <b>A1 Receipts</b>                                    |                                        |                                      |                                     |                                 |                               |
| Donations/ reimbursement                              | 9087.82                                |                                      |                                     | 9087.82                         | 1718.00                       |
| Fund raising                                          | 13287.39                               |                                      |                                     | 13287.39                        | 47.00                         |
| Bequest                                               |                                        |                                      |                                     | 0.00                            | 419.00                        |
| Travel expenses refund                                | 0.00                                   |                                      |                                     | 0.00                            | 0.00                          |
| Presentation expenses                                 | 0.00                                   |                                      |                                     | 0.00                            | 0.00                          |
| Charities Aid foundation                              | 62.00                                  |                                      |                                     | 62.00                           |                               |
| Website maintenance                                   |                                        |                                      |                                     | 0.00                            | 0.00                          |
| Covid donations (lottery/ Wasps)                      |                                        | 12460.00                             |                                     | 12460.00                        | 4020.00                       |
| Booklet Orders                                        | 4668.69                                |                                      |                                     | 4668.69                         | 8292.00                       |
|                                                       |                                        |                                      |                                     | 0.00                            | 0.00                          |
| <b>Sub total (Gross income for AR)</b>                | <b>26995.70</b>                        | <b>12460.00</b>                      | <b>0.00</b>                         | <b>39455.70</b>                 | <b>14489.00</b>               |
| <b>A2 Asset and investment sales, (see table).</b>    |                                        |                                      |                                     |                                 |                               |
|                                                       | 0.00                                   | 0.00                                 | 0.00                                | 0.00                            |                               |
|                                                       | 0.00                                   | 0.00                                 | 0.00                                | 0.00                            | 0.00                          |
| <b>Sub total</b>                                      | <b>0.00</b>                            | <b>0.00</b>                          | <b>0.00</b>                         | <b>0.00</b>                     | <b>0.00</b>                   |
| <b>Total receipts</b>                                 | <b>26995.70</b>                        | <b>12460.00</b>                      | <b>0.00</b>                         | <b>39455.70</b>                 | <b>14489.00</b>               |
| <b>A3 Payments</b>                                    |                                        |                                      |                                     |                                 |                               |
| Stationery and postage                                | 376.17                                 |                                      |                                     | 376.17                          | 1104.00                       |
| Website hosting & Software                            | 1804.17                                |                                      |                                     | 1804.17                         | 860.00                        |
| Re branding & advertising                             |                                        |                                      |                                     | 0.00                            | 86.00                         |
| Courier cost                                          |                                        |                                      |                                     | 0.00                            | 180.00                        |
| Conference expenses                                   |                                        |                                      |                                     | 0.00                            | 0.00                          |
| Donation or development work                          |                                        |                                      |                                     | 0.00                            | 580.00                        |
| IT Development                                        |                                        |                                      |                                     | 0.00                            | 0.00                          |
| Sponsorship for other Group                           | 1530.65                                |                                      |                                     | 1530.65                         | 0.00                          |
| Mail Management                                       |                                        |                                      |                                     | 0.00                            | 0.00                          |
| Payment for the Hall                                  |                                        |                                      |                                     | 0.00                            | 622.00                        |
| Ins/ Legal costs                                      | 380.78                                 |                                      |                                     | 380.78                          | 370.00                        |
| Booklet orders/ design work                           | 19042.72                               |                                      |                                     | 19042.72                        | 8006.00                       |
| Travel exps ICU Meetings                              | 47.44                                  |                                      |                                     | 47.44                           | 1615.00                       |
| Travel expenses on behalf of ICU                      | 849.56                                 |                                      |                                     | 849.56                          | 1291.00                       |
| INACTIC Grant Funding (re imbursement)                | 1306.23                                |                                      |                                     | 1306.23                         | 1480.00                       |
| Start up fund for new Group                           | 400.00                                 |                                      |                                     | 400.00                          |                               |
| <b>Sub total</b>                                      | <b>25437.72</b>                        | <b>0.00</b>                          | <b>0.00</b>                         | <b>25437.72</b>                 | <b>16013.00</b>               |
| <b>A4 Asset and investment purchases, (see table)</b> |                                        |                                      |                                     |                                 |                               |
|                                                       | 0.00                                   | 0.00                                 | 0.00                                | 0.00                            |                               |
|                                                       | 0.00                                   | 0.00                                 | 0.00                                | 0.00                            |                               |
| <b>Sub total</b>                                      | <b>0.00</b>                            | <b>0.00</b>                          | <b>0.00</b>                         | <b>0.00</b>                     | <b>0.00</b>                   |
| <b>Total payments</b>                                 | <b>25437.72</b>                        | <b>0.00</b>                          | <b>0.00</b>                         | <b>25437.72</b>                 | <b>16013.00</b>               |
| <b>Net of receipts/(payments)</b>                     | <b>1557.98</b>                         | <b>12460.00</b>                      | <b>0.00</b>                         | <b>14017.98</b>                 | <b>-1527.00</b>               |
| <b>A5 Transfers between funds</b>                     | <b>0.00</b>                            | <b>0.00</b>                          | <b>0.00</b>                         | <b>0.00</b>                     | <b>0.00</b>                   |
| <b>A6 Cash funds last year end</b>                    |                                        |                                      |                                     |                                 |                               |
| <b>Cash funds this year end</b>                       | <b>1557.98</b>                         | <b>12460.00</b>                      | <b>0.00</b>                         | <b>14017.98</b>                 | <b>-1527.00</b>               |

| Section B Statement of assets and liabilities at the end of the period |                         |                                                                                     |                               |                              |
|------------------------------------------------------------------------|-------------------------|-------------------------------------------------------------------------------------|-------------------------------|------------------------------|
| Categories                                                             | Details                 | Unrestricted funds to nearest £                                                     | Restricted funds to nearest £ | Endowment funds to nearest £ |
| B1 Cash funds                                                          | Bank Account            | 30674.30                                                                            | 0.00                          | 0.00                         |
|                                                                        | ICU Reserve             |                                                                                     | 6000.00                       | 0.00                         |
|                                                                        | Covid funding           | 12460.00                                                                            |                               |                              |
|                                                                        |                         | 0.00                                                                                |                               | 0.00                         |
|                                                                        | <b>Total cash funds</b> | <b>43134.30</b>                                                                     | <b>6000.00</b>                | <b>0.00</b>                  |
| (agree balances with receipts and payments account(s))                 |                         |                                                                                     |                               |                              |
| B2 Other monetary assets                                               |                         | 0.00                                                                                | 0.00                          | 0.00                         |
|                                                                        |                         | 0.00                                                                                | 0.00                          | 0.00                         |
|                                                                        |                         | 0.00                                                                                | 0.00                          | 0.00                         |
|                                                                        |                         | 0.00                                                                                | 0.00                          | 0.00                         |
|                                                                        |                         | 0.00                                                                                | 0.00                          | 0.00                         |
|                                                                        |                         | 0.00                                                                                | 0.00                          | 0.00                         |
|                                                                        |                         | 0.00                                                                                | 0.00                          | 0.00                         |
| B3 Investment assets                                                   |                         |                                                                                     | Cost (optional)               | Current value (optional)     |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
| B4 Assets retained for the charity's own use                           |                         |                                                                                     | Cost (optional)               | Current value (optional)     |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
|                                                                        |                         |                                                                                     | 0.00                          | 0.00                         |
| B5 Liabilities                                                         |                         |                                                                                     | Amount due (optional)         | When due (optional)          |
|                                                                        |                         |                                                                                     | 0.00                          |                              |
|                                                                        |                         |                                                                                     | 0.00                          |                              |
|                                                                        |                         |                                                                                     | 0.00                          |                              |
|                                                                        |                         |                                                                                     | 0.00                          |                              |
| Signed by one or two trustees on behalf of all the trustees            |                         | Signature                                                                           | Print Name                    | Date of approval             |
|                                                                        |                         |  | Philip Smith<br>Mo Peskett    | 25/4/2021                    |





CHARITY COMMISSION  
FOR ENGLAND AND WALES

## Independent examiner's report on the accounts

### Section A

### Independent Examiner's Report

Report to the trustees/  
members of

Charity Name

ICU Steps.

On accounts for the year  
ended

2020 - 2021

Charity no  
(if any)

1169162

Set out on pages

I report to the trustees on my examination of the accounts of the above  
charity ("the Trust") for the year ended

Responsibilities and  
basis of report

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.

Independent  
examiner's statement

[The charity's gross income exceeded £250,000 and I am qualified to  
undertake the examination by being a qualified member of [insert name of  
applicable listed body]]. Delete [ ] if not applicable.

I have completed my examination. I confirm that no material matters have  
come to my attention in connection with the examination (other than that  
disclosed below \*) 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
- 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.

\* Please delete the words in the brackets if they do not apply.

Signed:

Date:

17/06/2021

Name:

CHRISTOPHER HICKS

Relevant professional  
qualification(s) or body

ACCA

(if any):

Address:

FLAT 2 HANGSTONE HOUSE, 5 ST  
JOHNS AVENUE, CLEVEDON,  
NORTH SOMERSET, BS21 7TQ

## Section B

### Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.