



# Executive Summary- Annual Report: Order of St John Organ Donation Awards Ceremonies 2018



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**With thanks to all those individuals who have given a lifesaving legacy by donating organs for transplantation.**

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**We would like to also thank the Donor Family Network for their wise counsel and guidance.**

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## **Executive Summary**

During the Autumn of 2018 there were 37 St John Awards ceremonies that took place across the UK. This is the sixth year of successfully facilitating the posthumous Award presentations to 765 families. In the six years some 4,887 families have received the Award in recognition of their loved ones Organ Donation. The 2018 invitations to Organ Donor families were for a nine-month period, hence three-quarter year data, this is due to implementing a change in when these ceremonies are held in 2019 (from Autumn to Spring).

Total invitations to the 37 regional ceremonies represented 1207 deceased Organ Donors in the UK, these were sent to the donors next of kin. The regional teams received a 63% positive expression to receiving a posthumous award. From the positive expression 66% wanted to attend a ceremony and 34% requested the award by post. From the twelve regional teams there was a variation from 27% ceremony attendance in the South East to a 68% attendance in Scotland. There was no response from 34% of those invited and 2% declined the Award, with a general theme of it being too soon and a wish to be invited for the following year. There were two Special Award presentations of a glass memorial plaque to families. These were held in Surrey and London.

This is the first year that we have nationally evaluated the family's experiences of those that attended the ceremonies. From the 504 donor families that attended the Award ceremonies we received 178 feedback responses, 35% of those that attended. All responses were positive with "good and excellent" in regard to their overall feelings about the ceremony, communication and venue, detailed suggestions for future ceremonies in Family feedback section 4 page 11.

## 1.National Invitations and attendance six-year data

**Table 1.** NB: 2018\* data represents 9 months 01/04/2017-31/12/2017

	2013	2014	2015	2016	2017	2018*
<b>Number of Ceremonies</b>	<b>35</b>	<b>42</b>	<b>36</b>	<b>40</b>	<b>37</b>	<b>37</b>
<b>Total invitations sent</b>	<b>1122</b>	<b>1286</b>	<b>1288</b>	<b>1348</b>	<b>1417</b>	<b>1207</b>
<b>Declined or no expression %</b>	-	-	-	-	-	<b>28/413 2%/ 34%</b>
<b>Donor Families attending ceremonies</b>	<b>357</b>	<b>549</b>	<b>498</b>	<b>550</b>	<b>646</b>	<b>504</b>
<b>% of total invites that attended</b>	32%	43%	39%	41%	46%	42%
<b>Postal Award</b>	<b>301</b>	<b>291</b>	<b>298</b>	<b>336</b>	<b>296</b>	<b>261</b>
<b>% of total invitations for postal award</b>	27%	23%	23%	25%	21%	22%
<b>Total Awards presented Combined postal and ceremony (% acceptance)</b>	<b>658 (59%)</b>	<b>840 (65%)</b>	<b>796 (62%)</b>	<b>886 (66%)</b>	<b>942 (66%)</b>	<b>765 (63%)</b>

In 2019 we will be exploring the declined or no return of expression from the invitation letters, this equates to 34% of those invited. There is a regional variation between the Organ Donation Services Teams (ODST's) for no response or expression, 13% Northern Ireland to 44% in London. These two ODST's also represent the smallest invitation list to the second largest (see section 3. Regional Invitation and Attendance Data). It should also be noted that the London area experiences a high transient population. There will be further focus work taking place in 2019 to explore the no response or expression of 413 families. This will involve both the national project committee, representative from the Donor Family Network, Statistical Department, OSJ links in the ODST's and the Donor Care, Donor Records Department, NHSBT.

## 2. National Special Ceremonies presentation of a memorial glass plaque. (For complete summary go to Full Annual Report)

There were two Special Award presentations of a glass plaque to families, both originated from the South Wales Organ Donation Services Team. In both cases the families were experiencing disunity in their relationships. These presentations were given by Lady Hamilton of Dalziel at Betchworth House, Surrey and Mr Michael Messinger Chancellor Order of St John, at St Johns Gate, London. Both recipients and their families were very grateful for the experience to honour their loved one.

## 3. Regional Invitations and attendance data 2018\* Nine months 01/04/2018-31/12/2018

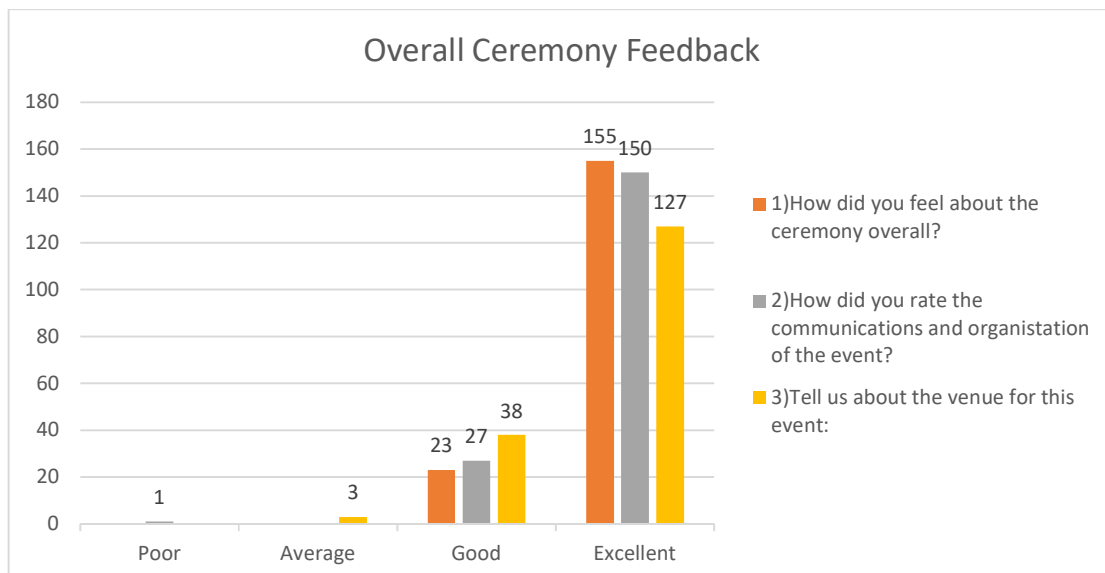
The ceremonies are organised by the local County Priory Group Chairs in response to the area's bespoke requirements, hence they are all slightly different. (Please see full Annual Report for in depth Regional Information).

## 4. Feedback from Ceremonies

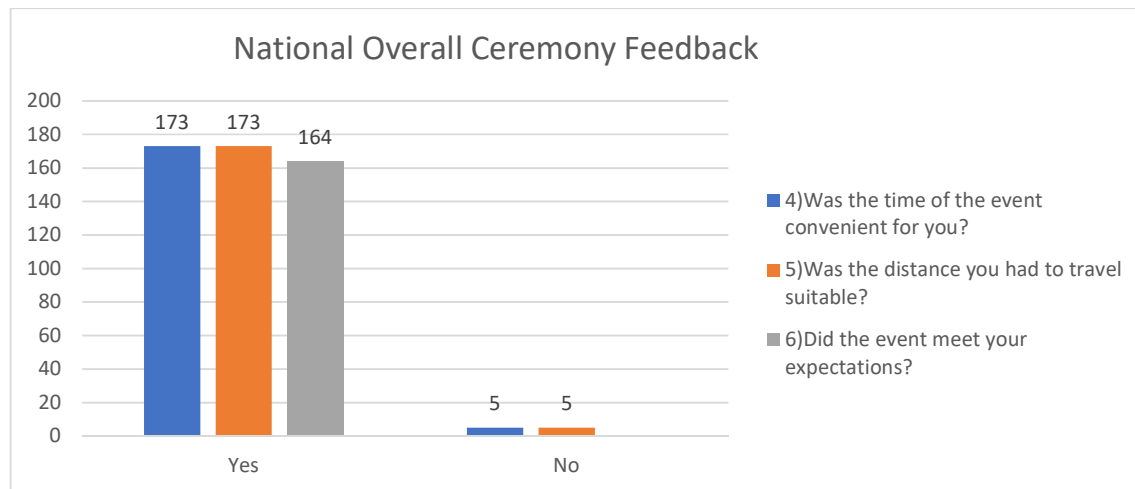
Donor Family Ceremony Attendance Feedback. (For complete summary go to Full Annual Report)

Feedback was requested from the next of kin where there was attendance at a ceremony. The questionnaire was posted and asked to be returned in a prepaid addressed envelope to the regional office where the initial ceremony invitations originated. There was a response rate of 35%, we have discussed improved ability to complete these for the future, via email. In many cases the photographs taken at the event are also emailed, this may elicit a better response rate in the 2019 ceremonies.

**Table 2a** Data requested from the twelve Organ Donation Services Teams for the 37 ceremonies:



**Table 2b**



### **Family Feedback**

The families evaluated the ceremonies overall very highly, documenting feelings of honour and pride in their loved one's recognition. The attendance of both Order of St John staff and the Specialist Nurses in Organ Donation has also been a common theme words such as empathetic, great comfort, welcoming and so pleased to see them again. There is specific Regional and Ceremonial feedback that will be supplied to each region and County Priory Chair.

For consideration and forward planning, there are some national key themed suggestions to improve the ceremonies that families have made, grouped into specific categories;

### **Communication and Organisation**

- There were two comments about invitations going to those relatives address who signed the consent form not the requested next of kin.
- "Information about where to park and if there is a cost would be helpful within the invitation letter".

### **Venue and Catering**

- "Although adequate, a venue with elevated status may have been more appropriate".
- "May have been difficult for frail disabled persons, ensure the whole service is at one venue some attendees could not climb the stairs (where the refreshments were served)".
- "Having a planned named table was comfortable and supportive with my family".
- "Good lighting so faces can be easily seen".
- Comfortable room temperature, there were some extremes reported.
- Microphone availability and acoustic testing before the ceremony.
- "Having soft drinks would have been better as well as tea/coffee, maybe water on each table".
- Cake biscuits were appreciated some enjoyed a full buffet.

### **Time**

- Ceremonies vary from late morning to early evening; many comments were appreciative of the time they attended.
- "Ideally not a Friday night, early evening was a good time".

- “The time was fine but I missed the part about needing to be seated and only saw start time. I would ensure this is highlighted”.
- “I had to take a day off work to go. Maybe for some a weekend would be more convenient”.

### **Travel/Parking/Location**

- “The venue was lovely, but parking was difficult fortunately I was able to walk”.
- “A little plan of parking and access to the entrance would have helped as we were unfamiliar with the area”.
- “Parking and access were awkward for disabled attendees”.
- “Perhaps more explicit information regarding buses and road names to reach the venue. This would apply only to people not too familiar with Edinburgh”
- “Only downside is parking costs and availability”

### **Ambience and General Comments**

- Some families found going up to be presented with the award, nerve wracking and too formal. They would have preferred to be sat with their family.
- Only thing I would change is getting medals sooner, so you don't have to sit through the whole event worrying/nervous before you go up”
- “Some families expressed wanting to mingle and talk with each other but found this difficult as were seated at tables”.
- “As a chaplain was in attendance, it would have been nice for a prayer of thanks, suitable for all faiths or none, at the beginning and a blessing at the end to send people on their way”.
- “it would have been so lovely to have a moment of reflection while a roll call of names could be read out, so comforting to hear your loved one’s name read out loud”.
- “Did not feel that "award" was the right word to call it. Maybe could use "recognition" ceremony. Award to us means somethings you have achieved by hard work and this was not something we wanted to achieve”.
- “Maybe photos of the donors would be nice for future services, so you can see the great people that donated”.
- “I did feel uncomfortable during the service with the over use of 'sacrifice' to describe the donors as it was a conscious decision when alive and a benefit to others on their passing. It's no sacrifice when your passed”.
- “Maybe some commitment from Government so a short speech from a local MP would also be nice”.

### **NHSBT Operational leads feedback**

The overall feedback for the 2018 ceremonies was positive, with 1 complaint submitted (Appendix 1.) This related to a Donor Family from 2016 in the South West Team where a family did not receive an invitation to any Ceremony. Investigations into this with the SWODST and Donor Family Care, Donor Record Department show that there was an administration error during the cross over period and handover of new processes. Data extraction is now utilised to prevent any further occurrence.

An operational feedback telecom was held with Regional Office Managers (ROM) chaired by Lynne Woolcocks on the 4<sup>th</sup> January 2018.

### Key points raised by the ROM's and attending Specialist Nurses and Team Managers were:

- All ceremonies were well evaluated
- How essential the pre-meets were to smooth running; at least an hour before the event to discuss the running of the ceremony, highlighting any potential challenges, sound checks, introductions and roles and responsibilities.
- A few families wanted to bring more than 3 guests this was managed by asking those families to call one week before the ceremony to check capacity, no complaints from families about this system.
- There has been expressed apprehension regarding uptake by families for 2019 ceremonies due to the short time between donation and invitation being sent for some families, ranging from 13/14 months to five weeks. The ceremony may be held as close to twelve weeks following death and donation

### Suggestions for improvements:

- Amend the photo log for inclusion of an email address.
- Design an electronic evaluation form to email families alongside the photographs from the ceremony.
- All ceremonies to have a pre-meet one hour prior to the ceremony starting.
- All ceremonies to have a short feedback session at the end of the ceremony.
- All regions to have a mop up and forward planning meetings.
- Update CPG guidelines to expand the invoice payment section.

### County Priory Chair Feedback

This is a summary of the feedback from 81% of the CPGs who planned and facilitated a ceremony. Overall the responses were very positive about the collaboration and organisation between CPG's and NHSBT local regional teams. Many commented on witnessed and verbal positive family experiences at the ceremonies.

Most found the venues and catering easy to book, although 9% of respondents expressed difficulties due to: lack of suitable civic buildings and the commercial venues expensive to hire. One CPG found it difficult to organise the ceremony as it was their first experience of doing this. One CPG reported that it would have been difficult without the financial support of a local Councillor. 77% found it was easy to recover costs for the catering, with a further 9% finding this difficult. 12% did not recovering the cost, in these cases some were funded by personal contributions and some from other sources

91% of respondents received the organisational information (final guest list) from NHSBT in a timely manner, one CPG felt that ten days prior was not long enough. 69% of Chairs were able to hold a short briefing session before the ceremony with St John, NHSBT staff and volunteers, these improve communication and expectation for the ceremonies smooth running. 89% felt that they received timely and adequate support from the CPG national office, some reported only requiring to liaise with local regional NHSBT colleagues. 57% of the ceremonies Awards were presented by the Lord-Lieutenant and in other cases a mix of Deputy Lord-Lieutenants, High Sheriffs, Lord Mayor and other local dignitaries.

### What went well:

- Opening and closing remarks put families at ease with a warm welcome and a table "host".
- Less formal arrangement with the Lord-Lieutenant meeting families individually



- The support of NHSBT and CPGs to families before the ceremony.
- The time spent by the Lord-Lieutenant and Lord Mayor talking to families after the ceremony.
- Ceremonies have settled into a good routine - SJA volunteers spent an hour chatting to families about their loved ones after the ceremony.
- Receiving earlier information.
- The involvement of the SNODS was extremely valuable and the Regional NHSBT Administrator and her team were a pleasure to work with.
- The Lord-Lieutenant in uniform is much appreciated.
- The Cathedral flower guild made a posy with a candle for each family. The Lord-Lieutenant lit a central remembrance candle from which an SJA Cadet lit each of the family candles when the Lord-Lieutenant spoke to them.

#### Suggestions for Improvement:

- CPGs made aware by NHSBT of any difficult or high-profile donations that were already in the public domain, recognising that there are issues of confidentiality and sensitivity.
- Pre and post mop up / debriefing and planning meetings with NHSBT and CPG colleagues that will attend the ceremony.
- Youth involvement and memorial candles.
- Raise the SJA regional team awareness of this noble service, invitation SJA Regional Director.
- Better PR.
- Signage to the event.
- A quick joint debrief after the ceremony to clear up or highlights any points.
- Availability of a St John/NHSBT pull up banner at each ceremony

## **6. Financial Data**

504 award x £26.50 = £13,356 budget

Estimated costs for 2018 ceremonies are broken down into:

- Venue/Catering - £9148.17
- Translation - £624.43

**Total for venue, catering and Translation £9772.60** excluding Photography

- Photography - £5593.20 paid for by communications budget

## **7. Media Summary.** (For complete summary go to Full Annual Report)

Our coverage provider Kantar held 60 articles which were attributed to the Order of St John, and a further 1 which had not been captured were found online.

The reach of articles was 2,776,672. This is a decrease from the previous year's cuttings. This can be attributed to a smaller number of national stories. The reach is expected to increase as due to competing team demands some of the releases were issued later than in previous years. The Express and Star, the Manchester Evening News and the Liverpool Echo which are all large regional newspapers are planning larger features and are speaking directly with the families to plan these pieces

The total number of articles captured was 60 which is a slight increase on the previous year due to the NHSBT press office issuing further regional releases. This was the first year the press office took on responsibility for the regional releases and interest from regional media was very good with many requests to speak to families. This took additional resource and will be taken in account when issuing releases in 2019. The regional interest allowed us to speak to more families across the country and while the reach is not as large in media numbers; the ongoing relationships with these families will allow us to work with them across a number of platforms, including our social media pages, the website and future campaigns.

As a case studies officer this is an important part of the role and I have established ongoing relationships with over 30 families.

## **8.Summary**

This is the sixth year of successful collaboration between Order of St John and NHSBT in facilitating the posthumous Award presentations to 765 families and marks the end of the Autumn Awards. From Spring 2019 we look forward to promoting the Ceremonies in warmer weather, this may ease some of the organisational challenges and allow for easier travel for the Award recipients. In the past six years some 4,887 families have received the Award in recognition of their loved ones Organ Donation, through presentation at a Ceremony or postal.

The national evaluation from the Award attendees has given us first-hand information from individuals experiences to consider in our future planning. From the 504 donor families that attended the Award ceremonies we received 178 feedback responses, 35% of those that attended. All responses were positive with “good and excellent” regarding their overall feelings about the ceremony, communication and venue.

We look forward to honouring the Tissue Donors in the United Kingdom from Spring 2019 with a Citation Award signed also by the HRH Duke of Gloucester on behalf of Her Majesty Queen Elizabeth II.

## **Appendix 1**

### **Complaint Summary: Donor family member were missed off the invitation list in 2017**

**Initial complaint** – Family contacted NHSBT regarding another matter but also mentioned they had not been invited to a ceremony

**Response** – Local team Manager apologised to the family and they will be invited to the 2019 ceremony.

**Investigation Outcome** - Data extracting was mid change in 2016 when the regional administration of donor files moved to the Donor records department.

**Learning** – Practice and processes have been changed since 2016. The details are sent directly to the Regional Teams Administrators from the statistical department in NHSBT, in a weekly generated report. The regional administration team then input these details into regionally held database for the OSJ invitations. Finally, all these details are cross referenced by the regional administration against the patients electronic file (Donor Path).