

CCPA Annual Report 1st April 2018 – 31st March 2019.

Background to the Charity and the Plan Made for the Year as above.

Since its inception as the National Alliance of Childhood Cancer Parent Organisations (NACCPO) in 1999, this Charity has been developing and adapting according to the human and financial resources available. Its name was changed to Childhood Cancer Parents Alliance (CCPA) in 2010 and the Constitution fully revised in 2016. It continues to be a Membership Organisation with member groups of varying sizes all with the aim of working to meet the needs of families of children and young people with cancer.

The key objectives continue to be at the heart of all that CCPA does:

- supporting the needs of families affected by childhood cancer, including wider family members and particularly those without access to an appropriate group;
- supporting member organisations in developing their operations and activities with similar families;
- promoting networking and interaction between parents, families and member organisations;
- maintaining regular communication and provision of information to families and member organisations;
- increasing public awareness of childhood and young people's cancers;
- representing member organisations nationally and internationally.

Back in January 2017, the Board had decided to build up the Stafford based CCPA office so that it would not only continue to be the administrative centre for the Charity, but would also focus more specifically itself on families affected by childhood cancer in that area. This would be a pilot study so that Stafford would be in a better position to advise and inform national member groups. As a result the well-established and ever enthusiastic Operations Manager now works full-time and continues to co-ordinate all activities. It was mutually agreed in December that the role of the Marketing Manager previously contracted on a Consultant basis, could be more effective if that person was local. Thanks were recorded to her for the progress made with the website and social media communications. The Operations Manager is now supported by a previously long term local Volunteer now as part-time Office Administration Assistant and who also profitably sells on eBay the better quality donations received by the charity.

It continued to be clear that within the capacity of the Board and the Staff, it was not possible to make progress with all the objectives of the Charity at the same time, so the previous years' seven point plan has been reviewed here for the year 1st April 2018 – 31st March 2019 and each is reported on below:

**Summary of Progress made with the Seven Points from Last Year's Annual Report:
from 1st April 2018 – 31st March 2019.**

1. To focus on the Stafford Area as a Pilot with More Intensive Attention Being Given to Increasing the Profile of the Charity Locally as well as Raising Funds to Support Families Affected by Childhood Cancer in the Area.

September 2018. Local support continued to grow through having more of a presence in the town, not least when running the third Pop Up Shop by courtesy of Stafford Guildhall Shopping Area in September. This was again opened by the Mayor of Stafford with the Town Crier and local press also in attendance. The quantity and quality of clothes and other goods donated towards this Pop Up Shop was again impressive with eye-catching window dressing including publicity for CCPA. Also available were Charity awareness raising items and information leaflets, activities for children and refreshments. Everyone involved, at whatever level, gained from the happy atmosphere with opportunities to meet and chat. Support was available for anyone needing to talk about what they were going through. Funds were raised to put towards future needs and experiences for families as well as the running of the Charity. Following all this progress and success, application was made for a similar shop for a further week in **March 2019.** However, the Guildhall suggested that CCPA should consider having a shop for 6 months. With key supporters the Operation Manager drew up a carefully thought out and costed initial Shop Business Plan and this was agreed by the Board and submitted. By the end of the period of this Annual Report (1st April 2018 – 31st March 2019), a contract was still awaited. By this time local generosity had continued to the extent that the Charity's storage of clothes and goods for the next shop was overflowing but no donations could be turned away.

In **December 2018** the third Gold Ribbon Ball was held at the Staffordshire County Showground with 242 attendees, a large increase on the previous year's 200. The event was hosted by BBC Radio Stoke's Lamont Howie who had met with the Operations Manager and volunteers at this year's Stafford Food Festival. Lamont connected so well with the charity that he offered his services FOC. We also had in attendance the Mayor of Stafford and the Stafford Town Crier who once again gave his services FOC to support the charity. The evening was a huge success once more with the chance to engage with the guests and share the work of CCPA in the hopes of attracting future support. The event raised an amazing £7500 (£4000 more than in 2017) due mainly to the auction, raffle and games on the evening. The hard work and dedication of our team of volunteers was a huge part of the success of this event and we would like to thank them greatly for their support.

Throughout the year a great many generous donations were received of gifts, food, prizes and tickets either to enhance events, but also used as gifts directly to the families living with childhood cancer. These included gifts for Mothers' Day and Fathers' Day as well as Easter eggs and Christmas selection boxes and presents. Families enjoyed outings to Pretty Pots, to Drayton Manor and to two Pantomimes. Other opportunities to get together including a parents' night out, lunches and coffee sessions and many activities for children and their siblings. The generosity of local businesses and members of the community included Tesco, the Co-Op and local Rotary Clubs as well as many smaller but also very supportive other businesses. Westfest generously made CCPA their Charity of the Year. This has all been impressive; it shows the continuing raising of the profile of the Charity locally and has contributed greatly to the support that CCPA has been able to give to families this year.

Energetic supporters raised awareness and funds by running in the Stafford 10k and half-Marathon, wearing t-shirts kindly sponsored by local businesses. Regular local radio and social media links also helped to keep the Charity in the public eye.

The CCPA Office continued to be run by the very experienced Operations Manager, herself a mother of a child who survived cancer, so is well aware of much that families are going through at such a difficult time. With the addition of the part-time Office Administration Assistant, the two members of Staff work well as a team bringing different skills and experience to fundraising, planning of events and keeping social media up to date. See Section 6 for more about the way the number of Volunteers increased and developed into a valuable team without whom managing such a range of events would not have been possible.

2. To Learn from the Events and Activities Held for Raising Awareness and Fundraising in the Stafford Area, and to Record the Processes and Information Gained so that they could be Passed On to Assist the Charity's Member Organisations.

Due to the increased workload from: fundraising events; the necessary networking and awareness raising required within Stafford; support work; training and management of the Volunteers, it was not possible for the Staff to take time to produce papers on key events and situations. Making the information available to the national Member Organisations could be an important aspect of support from CCPA. One event which has so far been written up fully for information is the Setting-Up and Running of a Pop Up Shop. There is also a sheet about holding a Swishing Evening. Ways will be considered to allocate time for other events so that learning situations can be written up by Staff or Volunteers ready for passing on, to support our Member Groups with their activities. More practically, it is planned that each type of event held will be set up with a recorded Budget that can be reviewed after the event to enable the Staff and the Board to evaluate its success.

3. To Continue to Provide Networking Opportunities for the National Member Organisations as well as Increasing Regular Communication with them; also to Maintain CCPA's Other National Involvements.

The CCPA Conference. Following the re-introduction of the CCPA Conference last year to provide our member groups with networking opportunities, information from established charities as well as learning and advice sessions, a Conference was organised for **June** at a conference centre just outside Stafford. Struggling for numbers, it became necessary to postpone this until **October**, but still the interest was not as we had hoped. We were very grateful to the speakers who agreed to present on the second date.

National Member Groups. The conference situation led the Board to re-examine the charity's relationship with its National Member Groups and it was realised that with all the recent focus on Stafford as a Pilot Area, this had slipped. We became aware that more personal contact was needed to find out how CCPA could help each individual group. Much of the **March 2019** Board Meeting was taken

up with each Board Member sharing their thoughts on the way forward and the Chair had also ensured that she had received comments from any absent members. All were delighted when an Executive Member of the Board with much experience in charities, volunteered to work on rebuilding the links with the National Member Groups. She began by travelling to meet face to face where possible and has talked to a range of size of charities. It is early days but progress has been made in raising the Board's awareness of what some other charities are doing. It is hoped that this will lead to us to understand the successes and concerns of our member groups so that CCPA can once again be a voice for them within the childhood cancer community to the benefit of all our membership. Looking ahead, it is also hoped that other Board Members will help with getting to know member groups and then at a later date, the on-going maintenance and further development of the national membership could become a paid position running as a second strand to CCPA.

Continuing Communication. We are grateful to the Marketing Manager who during her time with us, improved the CCPA Website arranging for sections to be re-written and updated and added more photos of our families and supporters. She also expanded our use of social media. With the change of Staff in **February**, the Operations Manager continued to post on Facebook, Twitter and added Instagram. The Admin Officer signed CCPA up to LinkedIn and also posts on Twitter. She also prepares and sends out monthly newsletters using Mail Chimp.

Wider National Connections. Board Members and the Staff continue to seek out newly formed Charities and Groups and the lists of Past, Present and Potential members drawn up from websites last year by a Board Member continue to be useful. Individual Board Members continue their involvements with their own charities and other national charities as well as having roles with the Cancer Intelligence Network, Children, Teens and Young Adult Clinical Reference Group and being on the Editorial Board of CCLG's Contact Magazine. They also attend the conferences of other charities and medical organisations, and taking part in research matters. The Small Charities Coalition has been found to be a good source of advice on many matters.

4. Not to Forget - but to Put On Hold - Active Involvement with International Childhood Cancer Organisations and Continue to Subscribe to Childhood Cancer International (CCI).

This was specifically discussed in **March** as there were differing views about it, partly due to the cost of annual membership of CCI - 600 Euros and unsuccessful efforts had been made to find out more about how the subscription is used. Hesitance was also due to another question – what does CCPA get out of being a member? Some board members felt that historically as NACCPO and now as CCPA, the charity holds the position of being the only fully paid up member of CCI in the UK and with this carry a vote. It was stated by a number of the Board that we should not lose this but pay it when due soon in **April**. It was also felt that this would hold our position whilst we take time to further consider our involvement by sending a delegate to any major conferences questioning what cost would be involved and what effect someone being there could actually have on such a large organisation.

However, it was said that without first building up our national membership we are not at the moment actually in a position to “be a voice” about matters. It was hoped that this will develop as the national arrangements noted above in Section 3 are actioned and then we could consider sending a delegate further afield. It was suggested that we should also explore closer links with CCI Europe. Following this meeting a formal vote was held by email with two questions:

- Question 1. *“Should CCPA’S annual subscription to CCI be paid this year?”* This resulted in agreement that this should be paid so that we keep our position as the only UK charity in CCI with a vote. This was subsequently paid;
- Question 2. *“Should we send someone to a major conference this year?”* This was not agreed as it was felt that we should first work to build up our national involvement and relationships with our Member groups.

5. To Continue to Hold the Much Valued National Support Workers’ Meetings as well as the Increase in Support for the Local Families.

National Support Workers’ Meetings. These national, long-standing, important meetings provided by CCPA used to take place two to three times a year to bring together dedicated support workers who provide support in hospitals, in the community and within Member Organisations for families affected by childhood cancer. The sessions gave them the opportunity to share their experiences, good news and problems within their roles and to pool ideas. Just one was held during the year and feedback from previous attendees has been that valuable though it is to get together with others working with similar experiences and workloads, it is becoming more and more difficult to take time out of a day to attend. These have been organised by our Operations Manager who has established many valuable links over the years but demands on her time have become an issue too. Within our review of our relationships with and provision for our National Member Groups (see Section 3), support for the support workers will be re-examined.

Increasing Support for Local Families. CCPA does not just provide special occasions, outings and gifts for families. For many years the Operations Manager has been available to offer herself or to find appropriate professionals for more personal, emotional type support for local families. Having increased the overall support for families affected by childhood cancer in the Stafford area, the many roles carried out by the Operations Manager all require more time. It is hoped that the admin help in the office may make it easier for her allocation of time to this area. It is planned during the forthcoming year to monitor this with the idea of employing someone suitable to add to the fulfilling of this role at some stage.

A Wider Range of Provision for the Families.

A range of activities, outings and events continued to be provided for families throughout the year. These have not only been for the whole family and bringing families together but also have included many activities for the children going through cancer and their siblings. Pamper Days for Mums and get-togethers for Dads plan to be repeated as well as provision for grandparents. The increase in funds raised as well as the many goods and services kindly donated, have made it possible to provide these activities.

6. To Build up the Team of Volunteers to Assist the Staff.

“Team Gold” started as the title for those Supporters who took on personal challenges such as 10k Runs, Half-Marathons etc and has grown to form a community which also includes: Fundraisers,

Donors of goods and services, Volunteers and Supporters, all contributing to the successes of the charity.

“CCPA Stars” has continued to grow as a stable group of regular and enthusiastic Volunteers who want to be able to do more. They hold regular meetings getting together to top up their training including the appropriate use of social media to support CCPA and also in developing good team work through confidentiality, reliability and responsibility. Some have moved on further by attending First Aid courses and obtaining DBS Cover. By running some small events themselves they continue to enable the members of staff to work on the larger events. This is both exciting and beneficial. The system of recording the impressive number of hours contributed by the volunteers has been improved (see Section 7) and can now be used to interpret and record these as an asset to CCPA’s charitable activities.

7. To Increase the Number of Trustees Adding a Wider Range of Skills and Experience to the Board.

Finance. Following the rapid loss of two potential Treasurers, it was realised that our whole financial system needed to be remodelled and put in place ready for any incoming Treasurer to be able to take it on and maintain it for the charity. During the year the decision was made to employ the Financial Director of VAST, a charity providing services and Support for Voluntary and Community Groups, Charities and Social Enterprises in and around Staffordshire, from whom we rent our charity office.

During the year VAST has reviewed our situation, given support and training to our Operations Manager to create and work an improved day to day system; they have produced a more user friendly presentation of our Year End Accounts adding in the valuable asset of all the donated gifts and hours of Volunteers’ time to this; they help with the financial aspects of employing our two members of staff and as we gained a bursary worth £500 for work on our website, they are continuing the updating and consistent branding of it for us. Following VAST’s recommendation, it was agreed that we would take on Quick Books Online and our Operations Manager and a Trustee have received training in the use of this system. Board Members are hoping that the outcome of all this will be that the whole of CCPA’s financial systems will be more user and reader friendly. We will then plan to recruit a Trustee/Treasurer.

The Financial Year to 31.3.19.

The Accounts at Year End show receipts of £84,263.45 and Payments of £57,713.16 giving an overall surplus of £26,550.29. With Cumulative Reserves from previous years the Balance stands as £73,109.30. For the first time, values outside these figures have been calculated to reflect the contribution of Volunteer Hours (calculated at the National Living Wage rate NLW) and that of Donated Goods as follows:

Volunteer Hours: 1891.50 x NLW	=	£17,023.50
Donated Goods :	=	<u>£13,105.19</u>
		<u>£ 30,125.69</u>

Events and Sponsorships account for 43% of Receipts whilst Donations account for 28% and Clothing Collection 18%. On the Payments side, Staff costs stand at 56% whilst Family Support accounts for 29% (excluding Volunteers Hours). Gift Aid has not been received so far but is provisionally valued for the Year at c£5,000.

Decision about Priorities for Action. During **October** all members of the Board took part in a questionnaire to help to clarify key areas to focus on as it was appreciated that we could not work on everything at once. The top two areas were clearly Finance and Staffing and as will have been seen in this Annual Report, positive progress has been made with both these priorities. The third area was entitled “Corporate” and which is also detailed in this report, bringing into focus the re-development of relationships with our national member groups which is just beginning.

Trustee Recruitment. It is recognised that during the forthcoming year, efforts must be made to increase membership of the Board to include people with specific skills and time to bring to the charity and possibly to be more local to the Stafford area.

The Way Forward. As seen above, the vision was reviewed and decisions made that CCPA continues with its three original strands – the **Local Work** (led by the Operations Manager) using her skills as fundraiser and providing support for the families with the assistance of the Office Manager; the second strand to re-develop / pull back - the **National Membership** side of CCPA (led by the generous offer of an Executive Board Member); the third being to maintain **CCPA’S membership of CCI** having decided to again pay the subscription to keep the vote we have as the only full member of CCI in the UK but to keep under review the value of further involvement and cost to attend conferences.

The intention continues to be to build up the Charity, working on the seven points as above with the key objectives in mind and our on-going desire to improve the situation for the many families struggling with the effects of childhood and young adult cancer on their lives.

*Report for the year 1st April 2018–31st March 2019,
for presentation at the CCPA AGM on 20th September 2019. Ros Francis, Chair.*

Members of the CCPA Board 31.3.18 – 1.4.19.

Name	Position	For Annual Report Year 31.1.18 – 1.4.19 (CCPA AGM held in September).
Ros Francis	Trustee, Chair and Secretary to the Board.	One year of three year term left to serve from September 2019. Has experience with Charity Commission formalities.
–	Deputy Chair	It was decided at the last AGM that another Trustee would take the chair if necessary.
–	Treasurer	Decided not appropriate to fill the role until new systems are put in place following two abortive attempts to have a Treasurer during the year. The role currently covered by employing the Finance Director of VAST assisting the Operations Manager with systems in the office. Trustee Sarah Doughty and Exec. Board Member Mike Francis both also contributing towards re-creating appropriate financial systems.

Jim Butler	Exec. Board Member. Started in Treasurer role.	3.8.18 - 11.2.19 Resigned due to ill health.
Mike Brookes	Trustee and Treasurer.	28.9.17 – 22.3.18. Resigned to live abroad.
Eddie Hinks	Trustee	Two years of the term of three years to serve from September 2019.
Margaret Johnson	Trustee	Two years of the term of three years to serve from September 2019.
Abby White	Trustee	Completing a three year term of office. Can stand for re-election in September 2019.
Sarah Doughty	Trustee	Two years of three year term to serve from September 2019.
Dai Hill	Exec. Board Member No election process but childhood cancer eligibility.	We hope he will continue to be able to be contacted for advice in the background.
Mike Francis	Exec. Board Member No election process but childhood cancer eligibility.	Currently contributing to the work to move CCPA's financial systems forward.
Sam Schoolar	Exec. Board Member No election process but childhood cancer eligibility.	Currently working to re-build CCPA's relationships with the national member groups.

CCPA Staff - 31.3.18 – 1.4.19.

Rachael Olley	Operations Manager	12.07.04 – the present.
Amanda Danells-Bewley	Marketing Manager	14.1.17 - 31.12.18
Jane Turner	Office Administration Assistant	1.02.19 – the present.



CHILDHOOD CANCER PARENTS ALLIANCE

Year to 31 March 2019

Receipts & Payment Account

	<u>Total 2019</u>	
Receipts		
Grants	£7,655.99	
Donations	£19,787.70	
Collection Tins	£287.46	
Just giving Donations	£3,174.19	
Memberships	£540.00	
Sponsorships	£1,105.00	
Fundraising Events	£25,280.06	
Just giving Events	£9,870.22	
Sale of Donated Goods	£1,258.02	
Clothing Collections	£15,074.80	
Miscellaneous	£230.01	
	<u>£84,263.45</u>	
Payments		
Family Support	£3,018.82	
Staff costs	£32,252.34	
Merchandise	£127.50	
Fundraising Expenses	£11,927.66	
Electricity	£0.00	
Phone & Internet	£1,177.49	
Printing and Stationery	£1,460.21	
Equipment	£435.94	
Rent	£2,524.56	
Accountancy	£958.22	
Volunteer Expenses	£38.06	
Trustee Expenses	£301.66	
Refreshments & Room Hire	£383.05	
Travel	£985.66	
Charges & Fees	£1,191.01	
Miscellaneous	£930.98	
	<u>£57,713.16</u>	
Surplus/(Deficit)	<u>£26,550.29</u>	
Reserves b/f	46559.01	
Reserves c/f	<u>£73,109.30</u>	£73,109.30



CHILDHOOD CANCER PARENTS ALLIANCE
Year to 31 March 2019

Notes to the accounts

1 Cash at Bank and In hand

	March
Cash at Bank	£72,288.69
Just giving	£0.00
Eventbrite	£0.00
Square	£72,288.69
Expenses owed	£0.00

2 Volunteer Hours

	April - Dec	Jan - March	Total
estimated volunteer hours	1648.5	243	1891.5
value of hours at national living wage	£14,836.50	£2,187.00	£17,023.50

3 Value of Donated Goods

	April - Dec	Jan - March	Total
Donated Goods	£3,177.50	£381.50	£3,559.00
Donated Trips and Activities	£9,719.50	£208.19	£9,927.69
Total	£12,897.00	£208.19	£13,105.19

20th September 2019.



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Year to 31 March 2019

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20th September 2019.