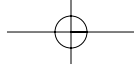




Ostomy Association of Ireland

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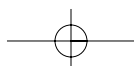
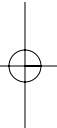
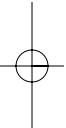
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Partnership -
Living life to the full with a Stoma or Internal Pouch

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1 PREAMBLE

The Ostomy Association of Ireland is the national support organisation for people who have a Colostomy, Ileostomy, Urostomy or Internal Pouch. Individuals of all ages can have a stoma as a result of having Cancer, Diverticulitis, Ulcerative Colitis, Crohn's Disease or following having a trauma to the abdomen. As a result of our Questionnaire in February – April 2018 members requested that the name Stoma should be in the name of our organisation. Considering that our membership included people from all three types of stoma it was suggested we consider calling the organisation The Stoma Association of Ireland. Members with an Internal Pouch did not feel included and it was put to the members to rename the organisation as :

THE OSTOMY ASSOCIATION OF IRELAND

It was decided by the Executive Committee in March 2018 that we look at the possibility of conducting a Survey/Questionnaire with all our members to gain valuable statistical information. The only statistical information which was available following a questionnaire carried out in 2015/2016 was a figure of 2000 people having stoma surgery in Ireland each year. Due to the restructuring and rebranding taking place at IA UK and its implications for IA Ireland we consulted with our members who said we should become independent with our own Logo and National Identity but maintain a close working relationship with IA UK with whom we were 54 years a Member Organisation. We needed to consult all our members and as a result we decided we needed to conduct a Survey/Questionnaire which would serve two purposes. The most important purpose was the need to consult with our members and obtain a mandate for change. The second most important purpose was to obtain vital statistical information about our membership through a Quality of Life Survey / Questionnaire which would help us to know our members better and to be able to serve them more effectively. The results of this Survey/Questionnaire helped the executive committee of IA Ireland prepare a Blueprint Document for the future as we looked ahead and planned for the needs of our membership. We have made great strides already in 2018 by increasing our footprint through the establishment of more Support Groups and hope we can further increase our footprint so we have 20+ SGs established before the end of 2019. We also want to ensure that we have a strong partnership relationship with our Ostomy companies who have given IA Ireland tremendous support over the last 54 years. We want to see that our relationship with the Ostomy companies is equitable and that all companies can support our efforts to serve our members through holding Public Meetings with Ostomy companies in attendance, so that they can promote their ostomy products. We are proposing that all Ostomy companies support the Ostomy Association of Ireland through a Corporate Social Partnership Sponsorship agreement, where all companies agree a Corporate Membership Fee which is the same for everybody. This will mean that the Ostomy Association Ireland executive will not be seeking additional sponsorship from companies during the year. The Corporate Social Partnership Sponsorship agreement which we are proposing for consideration will be outlined in this document under the Financial Heading.

Working in partnership must be seen as a Win : Win result for all Stakeholders - Members of the Ostomy Association of Ireland, Ostomy Companies and Medical Professionals.

THE OSTOMY ASSOCIATION OF IRELAND

was established as an unincorporated organisation on 1st January 2019.
Charitable Status will hopefully be ratified early in 2019.



2 GOVERNANCE

At the Autumn Public Meeting held on 20 October 2018 in the Ashling Hotel, Dublin 8, the following Officers were elected for the period 1 January 2019 to 31 December 2019:

Chairman	Paul Hughes
Vice Chairman	Keith Drayton
Secretary	Mark Sheehy
Assistant Secretary	Melissa Lyons
Treasurer	Ann Dold
PRO	Kevin Hughes

Each Local Support Group established throughout Ireland will elect a representative to be a Trustee on the Executive Committee.

The Executive Committee is required to meet 4 times in a year and if required extra meetings may be called.

The Executive Committee is responsible for :

- Creating a clear shared vision for the future of the Ostomy Association of Ireland.
- Providing leadership for the organisation.
- Formulating Policies and Plans for the future to realise the Objectives of the Organisation.
- Ensure that there is accountability and transparency to Stakeholders.
- Manage the limited financial resources of the organisation effectively.
- Ensure that the Ostomy Association of Ireland complies with all relevant policy and legal requirements.
- Oversee the management and assessment of risks to the organisation.
- The Ostomy Association of Ireland seeks to adopt a Code of Governance for Community and Voluntary Organisations early in 2019.

3 VISION

The Ostomy Association of Ireland seeks:

To help anyone living in Ireland whose colon has been or is about to be removed by a surgical procedure such as a Colostomy, Ileostomy, Urostomy or Internal Pouch.

To promote and co-ordinate research in bowel disease and other conditions leading to the removal of the colon, surgical procedures pertaining thereto, and related matters and further to promote the dissemination of knowledge gained by such research.

To keep people who have had stoma or internal pouch operations informed of all matters of interest by the periodic dissemination of information by organising Conferences, Seminars and Courses on topics of interest, and in any other matter which is charitable and which the trustees consider appropriate.

To liaise with the HSE (Health Service Executive) through our membership of the PCRS committee established to approve medical products for people who have a medical card.

To advocate for all people who have a stoma to be entitled and deemed eligible to have a medical card as a primary entitlement due to their life long medical circumstance.

To raise awareness with security personnel at airports throughout Ireland about people who have a stoma and to provide Awareness Training for security personnel.

To raise awareness about people with a stoma / internal pouch who need to access Toilet facilities in Public places so that Toilets which are accessible to people with a Disability can also be accessed by people with a stoma or internal pouch.

To work closely with other organisations for the benefit of all people with a stoma / internal pouch such as the Irish Cancer Society, Marie Keating Foundation and the ISCC (Irish Society for Colitis & Crohn's Disease)

4 AIMS

The Ostomy Association of Ireland seeks to Understand – Advise – Support its members. Major surgery involving a diversion of the bowel or bladder which necessitates having a stoma, which changes the bodily function of a person and can disrupt their lifestyle. People who have had a stoma for many years say that recovery is often assisted by having contact with people who have been through a similar experience. The following core activities are provided by the Ostomy Association of Ireland for people of all ages with a stoma or internal pouch.

- Local Support Groups
- Quarterly Journal. – Spring / Summer / Autumn / Winter
- Website / Facebook Page.
- Advisory Information Leaflets.
- Social Activities
- Visiting



5 OBJECTIVE

The Ostomy Association of Ireland's core objective is to help those facing stoma surgery to be able to return to a normal lifestyle as soon as possible after surgery. Because the members of the Ostomy Association of Ireland have a stoma or internal pouch we can with confidence say

We Understand - We Know - We Care.

The Ostomy Association of Ireland seeks to support all people in Ireland who have a stoma or internal pouch by providing information on stoma care, Through the establishment of Local Support Groups strategically located throughout Ireland we endeavour to provide a forum for people with a stoma or internal pouch to be able to meet and socialise with other Ostomates.

The Ostomy Association of Ireland seeks to work in partnership with stoma care nurses, medical professionals and Ostomy companies to improve the Quality of Life of our members.

The Ostomy Association of Ireland also seeks to develop a 'Visitor Training Programme' in collaboration with stoma care nurses, so that members who complete this course will be recognised and accredited as being competent to be requested to visit people who are about to undergo surgery or to visit them after they have had surgery. Persons selected to undergo the 'Visitor Training Programme' will be carefully selected and also vetted by An Garda Síochána as a person suitable to undertake the role as a visitor. This programme would be an Irish **Visitor Training Programme** which it is hoped will be devised jointly by a working group of members from the Ostomy Association of Ireland and a working group of Stoma Care Nurses (HSE and Company). People who successfully undertake the **Visitor Training Programme** will be awarded a Certificate. The Ostomy Association of Ireland will maintain a National Register with the names of members who have successfully completed the Visitor Training Programme and are available to be called upon if required.

6 STRATEGIES AND PLANS

Following on the success of more than doubling the number of Support groups in 2018 the Ostomy Association of Ireland will seek to further increase our footprint by establishing more Support groups throughout Ireland at key locations so that nobody wanting to attend a Support Group Meeting will have to travel more than 50km to attend a Support Group Meeting.

As part of the restructuring as we looked ahead to the next 5 years it was decided by the Executive Committee to establish three working groups :

1. Working group to develop a Blueprint for the Ostomy Association of Ireland.
2. Working group to examine the use of IT, Media & Communications by our members.
3. Working group to examine the possibilities for greater Social Interaction by our members.

The Survey/Questionnaire which was sent to over 600 people with a Stoma or Internal Pouch in Mid August has provided us with valuable information concerning our members and information on what our members want from the Ostomy Association of Ireland and the direction they want us to take over the next 3 to 5 years..

The cost of preparing the Survey/Questionnaire, printing and posting it out to members was made possible through an Educational Grant from United Drug Ltd. The Survey/Questionnaire is being analysed and a report on the findings will be prepared by two students who are graduates of the National College of Ireland, IFSC, Dublin 1. Both have M.Sc degrees one in Data Analytics and one in Cloud Computing. It is proposed that the results of the Survey / Questionnaire will be published in our new Irish Journal – Ostomy Ireland News. The first journal will be launched in time for the Spring Meeting in Dublin in the Ashling Hotel, Parkgate Street, Dublin 8 on 23 February 2019.

We hope that the results of the Survey/Questionnaire will provide us with a profile of people who have a stoma or internal pouch, this will give us valuable statistical information for the Ostomy Association of Ireland so that we can better understand and meet the needs of our members. It is also hoped that the information gained from the Survey/Questionnaire will be of value also to our Ostomy companies, Stoma Care Nurses and Medical Professionals who support our efforts to improve the quality of life of our members. The findings of this Survey/Questionnaire are primarily of importance for the future of the Ostomy Association of Ireland and the direction members want it to take for the future.

The Ostomy Association of Ireland acknowledges the close working relationship that we have had with IA UK for the past 54 years and we hope to continue to have a close working relationship with the Ileostomy and Internal Pouch Association UK.

We also want to have a close working relationship with the Colostomy and Urostomy Associations in the UK.

We are also applying to become members of the European Ostomy Association and the International Ostomy Association.

In February 2018 we became members of the WHEEL an umbrella organisation for The Charitable and Voluntary Sector Organisations in Ireland.

We hope to have our Charitable status confirmed early in 2019.

7 FUNDING

The Ostomy Association of Ireland is primarily funded through an annual membership fee paid by its members. Many members in addition to paying an annual membership fee also make a donation to support the organisation's costs.

Funding for our Public meetings comes from the Ostomy companies taking a stand to display their Ostomy appliances / products . Many Ostomy companies have also provided funding by paying for the cost of hiring a room in a hotel to hold Support Group Meetings, and have funded the cost of printing the IA Ireland quarterly Newsletter and also funded the cost of making a new Roll Up Banner in 2018.

The Executive committee working group on the future of the Ostomy Association of Ireland has examined our existing financial resources and is proposing changes which will be effective from 1 January 2019. Our membership subscription year has been extended so that the membership year runs from 1 January to 31 December each year. Following consultation with our Support groups earlier this year members indicated we should increase our membership fee which has remained unchanged for many years.

IA Ireland took a decision during the national financial crises in 2008 to continue sending our newsletter and the IA Journal to our members whose membership had lapsed. It has been decided to give an amnesty to members whose subscription had lapsed and encourage them to renew their membership again for 2019. A new scale of membership fees has been agreed :

Members aged under 60 on 1 January 2019 pay an Annual Membership fee of €20

Members aged over 60 on 1 January 2019 pay an Annual Membership fee of €15

Associate membership fees for anyone who is interested in supporting the work of the Ostomy Association of Ireland but do not have a stoma or internal pouch is as at the same subscription rate as Full members pay.

The Executive committee working group on the future of the Ostomy Association of Ireland also examined the level of financial support received each year from the Ostomy companies. It was decided we should try and ensure that there is an equitable arrangement established with the Ostomy companies whose support is vital in order to be able to provide a quality service for it's members.

It is proposed that we request Ostomy companies to make an annual payment as part of a Corporate Social Partnership Sponsorship agreement. This agreement would ensure that all Ostomy companies are supporting the Ostomy Association of Ireland by making the same annual payment.

The Ostomy Association of Ireland would not be seeking to ask companies to provide funding for any other additional support for the services it provides. The Ostomy Association of Ireland wants to ensure that we treat all Ostomy companies as equal and endeavour to promote the services of Ostomy companies on an equitable basis.

We are requesting Ostomy Companies to make an annual Corporate Social Partnership Sponsorship Payment of €2000 each year either as a single annual payment or as two payments of €1000 in January and July each year. The Ostomy Association of Ireland are proposing a Corporate Social Partnership Sponsorship funding package outlining the benefits for Ostomy companies in return for supporting the work of the Ostomy Association of Ireland.

Benefits for Ostomy Company Corporate Social Partnership Sponsorship

- Corporate Membership of Ostomy Association of Ireland.
- Attendance at three Meetings to be held each year in February, June and October.
- Linking of Ostomy Companies Websites with the Ostomy Association of Ireland Website.
- Free colour Full page advert in the Ostomy Ireland News Journal which will be published quarterly – Spring, Summer, Autumn and Winter.
- Receive Three copies of the Ostomy Ireland News Journal quarterly.
- Invitation for Stoma Care Nurses to make presentations and promote ostomy products at Support Group Meetings.
- Provide articles of interest for the journal.

The Dates for Meetings to be held each year for the next three years are :



YEAR 2019

23rd February 2019	Ashling Hotel, Parkgate Street, Dublin 8
29th June 2019	Clayton Silversprings Hotel, Cork
19th October 2019	Sligo Park Hotel, Sligo

YEAR 2020

22nd February 2020	Ashling Hotel, Parkgate Street, Dublin 8
27th June 2020	FitzPatrick Hotel, Waterford
24th October 2020	Clayton Hotel , Ballybrit, Galway

YEAR 2021

20th February 2021	Ashling Hotel, Parkgate Street, Dublin 8
26th June 2021	Castletroy Park Hotel, Limerick
23rd October 2021	Ballymascanlon Hotel, Dundalk, Co. Louth

Ostomy Companies will be in attendance with an exhibition of their Appliances and products from 12.00 to 14.00 Hrs before the meeting which will commence at 14.30 Hrs and will be followed with light refreshments. Tea and Coffee

The Dublin meeting held in February each year will be the Annual General Meeting of the Ostomy Association of Ireland



8 SUPPORT GROUPS

For information on where and when meetings will be held during 2019.

Please contact the following Group Co-ordinators.

BAGNALSTOWN : Co-ordinator Jamie Alcock 087 698 3719

CASTLEBAR : Co-ordinator J.J. McLoughlin 087 2300580

CAVAN : Co-ordinators Henry Durnin 086 8235157 and Rosemary Magnone 087 7984182

CORK : Co-ordinator Rose Flynnne 087 2953404

DROGHEDA : Co-ordinators Anthony Connolly 089 4418799 and Paul Hughes 085 7182405

DUBLIN : Co-ordinator Melissa Lyons 086 8099918

ENNIS : Co-ordinator Mark Sheehy 087 3843412

GALWAY : Co-ordinator Christina Walsh 085 2820630

GOREY : Co-ordinator Frank Norris 087 6204533

KILLARNEY : Co-ordinator Helen Carey 085 8182549

LETTERKENNY : Co-ordinator Rita Marron 074 9188887

LIMERICK : Co-ordinator Miriam Canty 087 6741930

NEWBRIDGE : Co-ordinator Veronica Lynch 087 7940850

SLIGO : Co-ordinator Mary McLoughlin 086 3608798

TULLAMORE : Co-ordinators Ann Dold 086 3074846 and Mark Sheehy 087 3843412

WATERFORD : Co-ordinator Keith Drayton 087 0666668

It is hoped to establish another 6 support groups during 2019.

9 CONCLUSION

Since the October meeting held in 2017 in the Ashling Hotel, Dublin 8, considerable progress has been achieved by increasing the service the Ostomy Association of Ireland provides for its members. The establishment of 10 more Support Groups SG's throughout the country has created the possibility for more of our members to be able to meet and socialise.

The Ostomy Association of Ireland Executive Committee has become more representative of the membership by having each SG nominate a representative to become a Trustee and contribute to making the Ostomy Association of Ireland more inclusive of its members views and hopes for the future direction of the organisation.

The Ostomy Association of Ireland is committed to Transparency and Accountability to all its Stakeholders – Members, Corporate Members and Associate Members by being honest, fair, respectful, transparent and open to public scrutiny and inspection. It is about being able to stand over what the Ostomy Association of Ireland does, the effective stewardship of funds and about ensuring quality. The Ostomy Association of Ireland seeks to make public its activities on behalf of its members and maintain the confidentiality of its members.

The Ostomy Association of Ireland through the working groups established 2018, carried out a detailed SWOT analysis exercise to examine the strengths and weaknesses of the organisation. The Blueprint Document for the future has looked at many different scenarios where the Ostomy Association of Ireland can have a positive result for its members.

The IT, Media & Communications working group examined thoroughly how best to communicate with our membership and the launch of our first journal Ostomy Ireland News in February 2019.

The Survey/Questionnaire completed in August 2018 by our members has provided us with valuable statistical information which was not previously available and which is most helpful as we engage in lobbying for a better quality of life for our members.

The Social Working group examined a number of options as to how we can encourage our members to participate and enjoy events we are planning for the future. In November the Sligo SG hosted their annual dinner dance and Ostomates from 17 counties attended the Dinner Dance which was attended by the Mayor of Sligo and a total of 150 guests. It was an excellent evening.

The Social working group are looking at holding a number of events, such as having a Charity Walk, Christmas Dinner Dance, Golf Classic, Race Night and also Table Quiz Nights as major fund raising events

The Ostomy Association of Ireland will continue to pursue a Partnership of Service with the Ostomy Companies and Stoma Care Nurses and Medical Professionals with whom we interact on behalf of our members so that together we can deliver a

Partnership -
Living life to the full with a Stoma or Internal Pouch



