



AWARDS FOR  
EXCELLENCE IN  
**PUBLIC  
RELATIONS  
2023**



# Best Use of Media Relations



Photo of the Ryan/McMahon family.

## Campaign

Every day counts with SMA

## Description of Campaign

To mark International Neonatal Screening Day, Red Flag designed a media campaign, on behalf of SMA Ireland and supported by Novartis, aimed at advocating for the addition of Spinal Muscular Atrophy to the heel prick test. This was complemented by additional targeted media campaigns in September and December.



## Public Relations Consultant

Red Flag Global



## Client

Novartis Ireland

## Background to the Campaign

Every baby born in Ireland is tested for a number of rare diseases as part of the National Newborn Bloodspot Screening Programme, commonly referred to as the 'heel prick test'. Ireland currently ranks 21st out of 30 European countries with regard to the number of conditions it screens for as part of the heel prick test. An increasing number of European countries have introduced spinal muscular atrophy (SMA), a genetic neuromuscular disease that can lead to death by the age of two, to their national heel prick tests. Ireland however has not rolled out testing for SMA, despite the availability of treatment. Early diagnosis and treatment of SMA, especially when treatment is administered to pre-symptomatic babies, results in a better prognosis and quality of life. Without it, children may require tube feeding, motorised wheelchairs, round-the-clock care with night nurses, and common illnesses like the flu are life threatening.

To mark International Neonatal Screening Day, Red Flag designed a media campaign, on behalf of SMA Ireland and supported by Novartis, aimed at advocating for the addition of Spinal Muscular Atrophy to the heel prick test. This was complemented by additional targeted media campaigns in September and December.

The National Screening Advisory Committee (NSAC) was set up to review and consider submissions for the expansion of healthcare screening of all kinds in Ireland. There are a number of different conditions, including SMA, which advocates are campaigning to be added to the heel prick test. There is also a swathe of other conditions, including screening for various cancers, under the purview of the NSAC's crowded agenda.

Red Flag was appointed to provide public affairs, communications and strategic counsel to aid Novartis in advocating for the addition of SMA to Ireland's heel prick test.

There are now several treatments available in Ireland, all of which are most effective when administered as early as possible. With SMA, 'time is neurons' and every day counts for babies in preventing disease progression. As a result, it is very important that babies are diagnosed as quickly as possible. A recent paper showed that six (25%) participants reported making ten doctor's visits before receiving a definitive SMA diagnosis, while ten (42%) reported having one or two health visits before a diagnosis.

Red Flag's campaign was treatment agnostic and did not refer to any specific therapy.

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## **Statement of Objectives**

The objectives of the project, agreed with our client, was to see SMA included in the heel prick test.

It was agreed that patient advocates and their families (i.e. SMA Ireland and other rare diseases advocates) should be the face of this campaign, with Novartis as a supportive partner. It was also agreed that success could take the form of a pilot programme.

In November 2022, SMA Ireland was informed that SMA was being considered as a priority condition, under preliminary assessment by HIQA for a Health Technology Assessment (HTA). In January 2023, it was announced that SMA will be the next condition to undergo a HTA. This is the process required in order for SMA to be added to the heel prick test.

The overall campaign encompassed both public affairs and strategic communications, but it was agreed that media tactics would be a critical component of the campaign, in order to engage the public, reach politicians in the media outlets that they read and consume, and create a drumbeat of advocacy.

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## **Programme Planning and Strategy**

### **Securing the advocacy voice**

In order to achieve our objective of adding SMA to the heel prick test, Red Flag advised that patient advocates (i.e. parents and their children) should be the face of the campaign, to make the most compelling case. We approached SMA Ireland and discussed implementing a mutually beneficial campaign to ensure SMA was added to the heel prick test as soon as possible, so that there would be an early diagnosis for future babies with SMA.

### **International Neonatal Screening Day**

Red Flag used media tactics in this campaign to create a drumbeat of content in the public consciousness about the need for SMA to be added to the heel prick test. We sought to reach key executive and political stakeholders, and wanted to ensure that when they picked up the paper or turned on the news that our campaign was reaching them.

Red Flag worked with SMA Ireland to provide media support to Liz McMahon and David Ryan, parents of Seán and Luke, then aged 2 and 4, who both have SMA. Luke was diagnosed with SMA at almost a year old and now lives with profound physical disabilities, requiring peg feeding and 24/7 care. His younger brother Seán however was diagnosed in utero and received gene therapy treatment at just a few days old. He now leads a relatively normal life. The contrast of the two boys' experience was used to develop a compelling media narrative around the importance of diagnosing SMA as early as possible through the heel prick test, so that it can be treated and lead to optimal outcomes, as experienced by Sean.

To lend authority to the compelling family story, Red Flag secured the support of Children's Health Ireland and Seán

and Luke's paediatric neurologist, Prof Declan O' Rourke. To round out the advocacy, we collaborated with SMA Ireland Director Jonathan O' Grady, and Vicky McGrath, CEO of Rare Diseases Ireland, to highlight the extent to which Ireland is lagging behind in rare diseases as a whole when it comes to newborn screening.

We identified International Neonatal Screening Day on 28 June as an opportunity for the McMahon Ryans to make the call to action for SMA to be added to the heel prick test. While international days are not always the most original opportunity to 'news jack' and convey our clients' stories, we felt the resonance of the heel prick test with every parent in Ireland, coupled with our powerful patient story, would make a sufficiently persuasive narrative to insert into the news cycle. Red Flag employed the hard graft of traditional PR tactics such as using key media contacts, direct pitching and call downs to gain traction.

Red Flag developed a compelling media narrative and identified key media targets across print, digital, radio and television. We advised our client on two possible approaches to the campaign: the first would be to pitch the story as an exclusive to one outlet, in order to guarantee coverage; the second was to take a 'far and wide' media approach, pre-pitching the story under embargo to a wider range of reporters. We decided the story was strong enough to take a 'far and wide' approach but made sure to manage expectations that while we could pitch to a reporter and secure their interest, the story is never over the line until we see it.

While health correspondents were our priority targets, we also pitched to tabloid features writers, who we felt were best positioned to tell the story from a human interest perspective. We additionally targeted women's and parenting focussed digital outlets.

In order to secure the best possible opportunity for the story to make it to print, we booked a photographer to visit the family in Mornington, Co Meath. This meant we could prepare our own selection of photos for photo desks with extended photo captions, and weren't reliant on a newspaper deciding if the story was worthy enough to dispatch a photographer. It also meant the experience was less intrusive for the family.

We utilised the experience of a Red Flag colleague who was a former tabloid newspaper editor, to identify the best photos to share with tabloid photo desks, and tailored the photo selection shared with these outlets.

As Prof O' Rourke's time was incredibly limited, we arranged for him to be interviewed directly by RTÉ News and the Irish Independent, as our priority Tier 1 outlets. We then drafted a series of quotes that we would supply to other interested reporters with his agreement.

We organised interviews with RTÉ News (featured on the Six One news and online), the Irish Independent, the Irish Examiner, TheJournal.ie, The Irish Sun, and The Irish Daily Mail and its digital outlets Extra.ie, Evoke.ie and rollercoaster.ie to be published on 28 June to mark International Neonatal Screening Day. The momentum of the story resulted in inbound media queries and further coverage of the story from Newstalk's Lunchtime Live, parenting website everymum, and digital outlet Her.ie, resulting in a total of thirteen media hits.

As a direct result of this media campaign, Deputy Pauline Tully and Senators Micheal Carrigy and Robbie Gallagher raised the issue of screening for SMA in the Dáil and Seanad, and eleven parliamentary questions were submitted by a cross-party range of politicians, following direct contact from SMA families with their local representatives. Pauline Tully was also interviewed on Northern Sound radio. Red Flag compiled a media and political coverage booklet which we shared with all stakeholders as a useful advocacy tool moving forward.

### **Follow-up feature in The Sunday Independent**

In September, Red Flag placed an exclusive feature with the Sunday Independent, in order to maintain media momentum. We found a new hook and used a different SMA family in order to create a fresh and newsworthy narrative.

Charles River Associates, supported by Novartis, conducted research which ranked Ireland 21st out of 30 countries in terms of newborn screening in 2022. Using this data as a 'new news' hook and to emphasise the urgency of expanding the heel prick test, we prepared a second SMA family for media engagement. Shane Whelan and Stefanie Vaz-Vieria, parents of baby Theo Whelan, coupled with our clinician voice in Prof Declan O'Rourke, were interviewed in the 18 September edition of the Sunday Independent; as the best selling newspaper in Ireland, this ensured the story got the widest possible reach.

## **Media coverage of Mansion House briefing**

In December 2022, Red Flag organised and hosted a briefing for politicians and health executives at the Mansion House with an expert panel of NGO voices, clinicians and patient voices. Red Flag also issued media invitations to the event, calling down all national news desks to secure attendees, as well as pre-pitching selected health correspondents. We additionally held a photo call and issued a press release following the event. We secured a discounted charity rate from our photographer and used the outdoor setting of the Mansion House, decorated for Christmas time, for the photocall. We had free use of the venue following permission from the Lord Mayor of Dublin to host the event.

The photocall utilised the McMahon Ryan family once more, as well as GAA star Aisling Donoher and her son Dan, who has SMA. Our pitching strategy resulted in media coverage on RTÉ Radio 1's Morning Ireland, RTÉ's 1pm lunchtime news, RTE.ie, The Irish Examiner and The Irish Independent. We provided media training and key messaging preparation for our spokespeople, SMA Ireland Director Jonathan O' Grady and SMA parent Aisling Donoher. Minister for Health Stephen Donnelly noted in the Dáil that he had listened to an interview with Jonathan O' Grady on Morning Ireland, and a number of politicians raised the issue in the Houses of the Oireachtas.

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## **Measurement**

A key objective of the campaign was to raise awareness among political and health executive stakeholders of the urgent need for inclusion of SMA in the heel prick test.

Red Flag's proactive media campaigning and other activities, including event management and stakeholder activation, resulted in key outcomes to advance the campaign. This included the placing of sixteen parliamentary questions, many of which directly used key messaging from the campaign. There were further relevant mentions of the issue in the Oireachtas by both Senators and TDs, as well as the Minister for Health.

In December 2022, the NSAC met for its final meeting of 2022, during which it recommended that SMA undergo a Health Technology Assessment (HTA) which is the first step in including it in the national heel prick test. This decision was announced in January 2023.

Outcomes that are directly attributable to Red Flag's media relations activities are detailed below:

Minister for Health Stephen Donnelly directly mentioned the campaign during a discussion about healthcare screening at the Oireachtas Health Committee. He noted an interview he had heard that morning, 6 December, with Jonathan O' Grady of SMA Ireland on RTÉ Radio 1's Morning Ireland (ahead of the Mansion House briefing).

The International Neonatal Screening Day (INSD) media campaign prompted Deputy Pauline Tully to address the media herself, advocating for the inclusion of SMA in the heel prick test on local radio station Northern Sound. She also discussed the issue in the Dáil.

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