

Malta, March 20, 2004

Working with the Media

Mr. Chairman,

Ladies and gentlemen,

On behalf of Epi-Suisse, the Swiss Epilepsy Association (Swiss Chapter of IBE), I would like to thank you for this opportunity to report on our experiences with the media. As you have most probably noticed, epilepsy is not a favorite subject of journalists. We will be sure of headlines when we can announce the first successful brain transplant or the discovery of a new wonder drug for the cure of epilepsy. But the reality is that epilepsy is a complex disease and its various aspects are difficult to communicate. Nevertheless, we must continually make the effort to gain the media's attention in order to inform the public about epilepsy. Because the public needs to know the facts about this disease and we need the public.

Introduction

In 2002 Epi-Suisse and the Swiss League Against Epilepsy (Swiss Chapter of ILAE) decided for the first time to organize a "Day of Epilepsy". The realization of this project was delegated to a four- person committee whose members were highly motivated and full of creative ideas. The composition of the committee remained the same in 2003 and 2004. As a first priority the goals of the Day of Epilepsy were defined:

Goals of the Day of Epilepsy

- Inform a broad spectrum of the public about the characteristics of epilepsy
- Increase understanding for persons with epilepsy
- Contribute to improving the social integration of them by reducing prejudices
- Promote that people with epilepsy deserve the same quality of life as anyone else

Already in the first discussion it became clear that the media would play a significant role since we wanted to reach the broader public and not just our own members. Our target audience remained at the forefront of our minds as we planned the campaign. We always asked ourselves, "Is this interesting to the media? Will editors and journalists be receptive to our message?" We agreed on the following fundamental points for the project:

Fundamental Points for the Project

- Each year the Day of Epilepsy would have a specific theme.
(Like our German colleagues we chose “Work and Epilepsy” in 2002, “Children/Adolescents and Epilepsy” in 2003, and “Sport and Epilepsy” in 2004. The focus on one theme aided communication. Presenting too many aspects of the disease at once would have been counterproductive.)
- The main event would include the participation of one or more well-known public figures, if possible.
(In 2002 we had an artist with epilepsy and a popular television moderator; in 2003 just the moderator, and in 2004 we are still searching for a prominent athlete.)
- In addition to speeches and discussion, the main event must offer something extra to spark the interest of the media.
(In 2002 we presented the “Swiss Epilepsy Report”. In 2003 we announced the educational program for children with epilepsy and their parents, “FAMOSESES”. Our presentation for 2004 is yet to be determined.)
- We wanted to provide the media and visitors with something concrete that would remind them of the Day of Epilepsy long after the event. (In 2002 and 2003 we distributed decals and, especially for the journalists, highlighters. In 2004 we are considering a printed band-aid, but we have not yet made a decision.)

Specific Media Initiatives

Early on we discussed which periodicals, which programs on radio and television, and which journalists were to our knowledge best suited for the topic of epilepsy. We gathered addresses of possible media contacts. Six months before the event we wrote our first letters to editors and program directors. In our letter we announced the Day of Epilepsy and offered to provide background material and interview partners, either doctors, patients, or family members of persons with epilepsy.

We created a special telephone number solely dedicated to the Day of Epilepsy and a special website.

For general information we produced a flyer that provided the main points for the theme of the day, for instance “Work and Epilepsy”. Since Switzerland has four official languages the

flyer had to be translated and printed in four versions. Switzerland's multi-lingual character also proved a problem when initiating contacts with journalists but more on that later.

We telephoned the key decision makers depending on the lead time of each media and referred to our letter. Anyone who showed even a vague interest was contacted regularly each month. Those who wished received substantial documentary material. We were never demanding, but always friendly and helpful. With journalists who already had written on medical topics we mentioned their earlier articles and referred to their special competence in this area. We put together a press packet which was available two weeks before the main event. It contained summaries of all speeches, information about Epi-Suisse, the Swiss League against Epilepsy and ParEpi, the Swiss Association for Parents of Children with Epilepsy. Moreover two fact sheets titled "What is Epilepsy?" and "What You Should Do in the Event of a Seizure". We provided flyers, decals and highlighters, as well as a schedule of events. Finally, the press packet contained a press release with a press deadline. The press packet was distributed to all the important editors and media personnel and was available at the main event.

We composed two press releases: one to announce the main event and a second to report on it. In the announcement, we focused on the main theme, for example, "Children and Epilepsy". In the second release, we emphasized the interesting new information such as the launch of the Epilepsy Report 2002 or the educational program FAMOSES. The press releases were written in German and then translated into French and Italian. A news agency disseminated the releases throughout Switzerland. We decided not to translate the releases into Romansch due to the scarcity of media in this language.

Nevertheless, a lengthy article on the Day of Epilepsy appeared in the Romansch press thanks to a physician who used the press releases to write in his native language. The doctor also translated the flyer in Romansch. I now arrive at an important point: our work with the media, and the entire campaign, would never have been successful without the efforts of many volunteers in all of Switzerland.

We made our press packet available to our colleagues in SESI, the epilepsy organization in the Italian part of Switzerland, and they used it for their own media contacts. Our colleagues in French-speaking Switzerland proceeded similarly. Six months before the event we sent a letter to all self-help groups and all the heads of neurological clinics requesting their assistance. As a result, patients and physicians in many areas of Switzerland contacted their local media and were successful in generating interest. Many made themselves available as

interview subjects, and others, especially physicians, wrote articles. Some self-help groups set up information booths in markets or hospitals and invited journalists there.

ParEpi brought an additional element to the campaign. All leaders of the regional groups received from the committee a sample letter to the editor whose contents could be adapted to their personal situation and sent to local newspapers. As a result, the letters had a personal look and appeared in various regions of Switzerland.

All the important newspapers near the location of the main event received a copy of the program for their events calendar. We did this to interest both visitors and journalists. In addition, we published an advertisement in 2003.

To summarize, here are the main elements of the media campaign:

Elements of the Media Campaign

- Personal contacts by letter and/or telephone
- Press packet
- Press releases
- Interview or articles by volunteers
- Letters to the editor
- Events calendar
- Advertisement

Results

We commissioned a media survey (ARGUS) for the period four weeks before and four weeks after the Day of Epilepsy, and so we were able to evaluate precisely whether our efforts bore fruit.

In 2002, 99 different media reported on epilepsy, including 51 newspapers, 4 radio stations, and one television station. By Swiss standards, and given the difficulties related to Switzerland's multilingual character, this was a wonderful result for us. We established that our own press releases were published 24 times; there were 17 letters to the editor; 15 articles based on the documentation that we had provided; and 43 articles which journalists had written independently.

In 2003, 54 media reported on epilepsy, including one radio station and four television stations. Our press releases were used only ten times, probably because the Day of Epilepsy was no longer a new event. Only six letters to the editor were published, but there were 50 independently written articles in various newspapers. Some newspapers even reported twice about the subject. Quantitatively, the response in 2003 appears somewhat diminished relative to 2002; however, 2003 was a success nevertheless because the independent articles were very detailed and informative. Furthermore, two television programs generated enormous interest: one was a well-known Swiss talk show that had invited a patient to appear on the show, and the second was the broadcast of a documentary film about epilepsy. This documentary film was inspired by a meeting with a journalist at the 2002 Day of Epilepsy. More articles appeared on epilepsy over all in 2003 because the subject already had become more familiar.

The Day of Epilepsy 2003 was accompanied by more than 25 events in different parts of Switzerland, at least five more than in 2002.

Media Response

	2002	2003
Total Media	99	54
Our press releases	24	10
Articles based on our publications	15	--
Independent articles	43	50
Letters to the editor	17	6
Radio	4	2
TV	1	4

Difficulties

Our greatest difficulty was contacting radio journalists. They never answered our letters and were not reachable by phone. We usually were transferred from one secretary to another and we were unable to establish a personal contact. Only a few local stations reported on the main event. They had received our press releases through an agency.

We were not spared disappointments: a journalist of a widely-read newspaper repeatedly promised a lengthy report on epilepsy and claimed that she was fascinated by the subject. Not one word has yet appeared.

There also were editors who complained that we pestered them with the “unattractive” subject of epilepsy.

In general we heard time and again that the expression “Day of Epilepsy” was not attractive for journalists. They had enough of all these days of dogs, Alps, or dyslexics. As a result, we began to refer only to our epilepsy campaign. We said in a friendly manner that every fall we tried to remind the public about epilepsy since 1 per cent of the population was affected. This usually brought amazement and generated interest. The presence of the media at the event itself was usually limited, however.

Many journalists called immediately before or after the event, so it was especially important to man the telephone a week before and a week after the Day of Epilepsy.

Radio reporters appeared unannounced or journalists wanted to do an interview over the telephone. Therefore, we had to establish in advance who was the appropriate contact for which area so that we could prepare and respond adequately.

Conclusion

The analysis of the media data after the events showed that two main factors had contributed to success. In addition to the well-prepared press packets and two widely-circulated press releases, personal contacts with journalists proved decisive. Many physicians and members of the self-help groups supported the campaign by phoning, writing, and meeting journalists.

In Switzerland the cooperation of self-help groups, physicians, patients and their families, Epi-Suisse, the Swiss League Against Epilepsy, ParEpi, SESI, and Eclipse was critical to the

success of the campaign. We were happy to note that numerous journalists told us, "We already have written down the dates. We remember last year's campaign." Epilepsy takes patience. This is true for a therapy as well as a public relations campaign. Small steps ultimately take you to the goal but you need to persevere. It is important that more and more people are informed about epilepsy and what it means for those who have this condition. A recent poll in Switzerland produced some very encouraging results with respect to general knowledge about epilepsy and the degree of understanding for the patients. We are on the right path.

Some Advice

- Journalists require the information that you provide to do their job. Do not hesitate to contact them.
- Journalists need recognition as we all do. Treat them like Very Important People. Do not demand, whine, or beg. The best approach is a friendly manner and clearly formulated information.
- Every single contact is important. Use the experience and network of partner organizations.
- Stay confident when the inevitable setbacks arrive.

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