Annual Report 2013

Together we can beat prostate cancer!
The Swedish Prostate Cancer Federation and its 26 regional associations support cancer patients and their relatives. We work to win more respect for and knowledge of the disease, and to advocate better care and more resources for research. The Blue Band is the symbol for the battle against prostate cancer.

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DIRECTORS’ STATEMENT

2013 has been the most active year in the history of the Federation
The year of 2013 was the year that we surpassed almost every single target. Successful lobbying paired with active media participation pushed prostate cancer front and centre – making it a disease that more and more people talk about.

- Regional meetings and our LYFTET training sessions were held in several cities during the spring.
- The Annual Assembly was held in April. Most of the Federation’s steering documents were revised and six proposals were addressed – all during lively debate. Anders Gyhlenius received this year’s honorary award.
- For the second time the Federation carried out a nationwide prostate cancer campaign involving more than 160 activities (100 activities in 2012), most of which took place in September.
- We have received considerably more attention from the media in the form of TV and radio coverage as well as articles in many newspapers around the country.
- We have been active in social media: Facebook (the number of followers for the Swedish Prostate Cancer Federation more than doubled in 2013), Instagram and Twitter.
- We started selling the Blue Band pin through the pharmacy chain Apotekssorgen and produced the Blue Moustache pin.
- The Federation created a brand new website that has twice as many visitors.
- The Foundation has received more revenue and can allocate more. The Foundation has become better known, resulting in more applications for research grants and more scholarship applications.

The Swedish Prostate Cancer Federation (SPCF) is a nationwide organization with 26 patient associations that work to increase knowledge about prostate cancer and provide support to men with prostate cancer and their relatives. Moreover, the Federation lobbies for better care, supports research and competence development, and influences public opinion through its own foundation.

At the start of 2013, the number of association members totalled 8,228, growing to 8,823 members by the end of 2013 – a 7% increase. The Board of Directors recognises an extensive and sound collaboration between the Federation and its regional associations. Revenue continued to increase which contributed to more activities. Administration, on the other hand, did not receive enough attention. The Board ruled on a number of measures, the implementation of which started at the end of the year, and all routines will be in place by the start of 2014.

Stockholm 11 March 2014

Alf Carlsson
Chairman

Torsten Tullberg
Director General
1. MISSION AND OBJECTIVES

About SPCF
The Swedish Prostate Cancer Federation, SPCF, was founded in 2006 and is a non-profit organisation of patient associations for prostate cancer in Sweden. The Federation has no affiliation with any political party or religion. SPCF is a continuation of the efforts of the National Organisation for Prostate Cancer founded in 1996.

SPCF's mission and objectives
The Federation assumes the perspective of patients and their relatives, and is tasked with:

- Advocating early detection of prostate cancer which improves the chance of a cure.
- Advocating better diagnostic and treatment methods, as well as effective rehabilitation and post-treatment care that considers the patient’s quality of life.
- Encouraging preventive and health-oriented initiatives in the field of prostate cancer.
- Conveying factual information to authorities, institutions and the general public about patient experiences and circumstances.
- Representing patient interests in contacts with authorities, institutions, organizations and the media.
- Advocating the formation of collaborations with medical experts, authorities, organisations, individuals in society and the business community.
- Advocating for and financially supporting research and development in the field of prostate cancer.
- Supporting the further education of personnel working in Swedish prostate cancer nursing, including financial support.
- Encouraging and facilitating the formation of patient associations.
- Supporting the information and counselling services provided by the patient associations as well as, but not limited to, their training, support and contact person services for patients and their relatives, and organising training sessions to improve the skills of patient representatives.
- Promoting and facilitating the exchange of experiences between patient associations.
- Participating in the activities of national and international societies that are significant for our organisation.
2. IMPROVE PROSTATE CANCER AWARENESS
The Swedish Prostate Cancer Federation is dedicated to spreading information about prostate cancer through various activities directed at educating and increasing the general public’s awareness of the illness and the importance of early detection. Early detection improves the chance for successful treatment, thereby alleviating the situation for the individual and his relatives. Early detection also reduces healthcare costs compared to treatment that begins after the disease has progressed. The Federation also conveys to institutions and government authorities factual information related to patient experiences and their circumstances.

Prostatanytt
Second only to our website, Prostatanytt is the most important instrument in providing information. Four numbers of Prostatanytt have been published under the management of Editor-in-chief Torsten Sundberg, who was also in charge of selling advertising space. Circulation has increased steadily, growing from 6,900 copies in 2012 to 9,000 in 2013. The members of Prostatanytt’s 2013 editorial council are:

- Mats Hedlund, Urologist
- Ulf Norming, Urologist
- Rolf Zimmerman, Oncologist
- Kristina Sjödin, Oncology nurse
- Christina Örum, relative
- Ola Lager, Prostatanytt’s former editor-in-chief

As the number of patient association members grows, so too does the circulation of Prostatanytt.

Ten issues of Nyhetsbrevet
SPCF sent its newsletter Nyhetsbrevet to the association chairmen ten times in 2013 (seven issues in 2012) so that they can update their members on the current situation in SPCF.

Design of a new website and continued improvements
Our members will be able to access information about prostate cancer through SPCF and the website will be SPCF’s main source for information. In March 2013 a newly designed, more extensive website was launched that includes a subscription to news about what the media is reporting concerning prostate cancer. Improvements have been made to the website throughout the year.

Social media
The Board of Directors adopted a social media strategy in 2013. The Federation’s Facebook page swelled from 300 followers in 2012 to 2,600 in 2013 and information from the Federation spreads far very quickly through Facebook. When we published an article about side effects in April, 400 people had read the article within one hour.
Spreading knowledge to many people
The Federation spreads information to its members on a continuous basis. The Federation’s ambition is to reach as many as possible of the 85,000 men who have prostate cancer and their families and close relations. Social media plays a major part and the Federation started using both Instagram and Twitter in 2013.

Writing and spreading brochures
Some 20,000 copies of SPCF’s four-page flyer was sent out to communicate information about the disease, create awareness about the September Campaign, gather donations to the Foundation and encourage members and other people to visit our website. The brochure Nästan alla män (Almost all men) was written and 30,000 copies were printed for the September Campaign and sent to healthcare centres in Sweden. The brochure explains to the general public what prostate cancer is.

Meetings and debates
Several of the Board’s members participated in meetings, panel debates and workshops (arranged by the Dental and Pharmaceutical Benefits Agency, the National Board of Health and Welfare, the Regional Cancer Centre, the Swedish Association of Local Authorities and Regions, etc.) in order to communicate the patient’s perspective and increase knowledge about prostate cancer.

Survey on prostate cancer patients’ perception of medical care
An important tool in improving forms of treatment involves ascertaining how patients feel about the care they receive. The Swedish Federation of Prostate Cancer Associations has taken part in a variety of surveys before and a Nordic survey funded by Astellas was sent out in 2013. This was the first time ever that a Nordic survey was made that focuses on what it is like to live with prostate cancer. Because advances in drugs are progressing rapidly, the survey will be a recurring aspect within the associations. The Federation is working to ensure that the right questions are asked and that the surveys complement each other.

3. SUPPORT FOR PATIENTS AND THOSE CLOSE TO THEM

Telephone counselling
The Swedish Prostate Cancer Federation’s office offered counselling and referral assistance to its members and those close to them. Counselling has grown from 9–10 phone calls per day between 2010 and 2011 to some 30 phone calls a day in 2013.

Email counselling
Also the number of questions sent in via email rose. From 10–12 mails a day between 2010 and 2011, the number of emails containing questions or from someone wanting contact climbed to about 75 emails per day.

Website counselling
A large section about prostate cancer has been placed on the Federation’s website. The section contains referrals, advice, radio programmes and video clips.

Encourage groups of relatives/close relations and therapy groups
SPCF has helped several groups to get activities up and running.
4. INFLUENCING PUBLIC OPINION

Efforts towards improving prostate cancer care

Throughout the year the Federation worked extensively to influence public opinion towards improving prostate cancer care. The Federation wants prostate cancer-related issues to be important in public opinion. Our work is primarily directed towards advocating better diagnosis and treatment methods, making medical and healthcare services more responsible for sexual dysfunction and incontinence, and improving the possibility to receive life-extending medication. In relation to the prevalence of the disease, there is too little prostate cancer research and SPCF is advocating more research in the field of prostate cancer.

Good prostate cancer treatment is the Federation’s primary issue.

Good prostate cancer care

The Federation has worked to spread its Requirement specification for good prostate cancer care. The document is a complement to the fundamental view that SPCF previously adopted and it has been introduced at Nordic and European meetings.

Efforts to secure approval for the use of life-extending drugs

Contact has been initiated to secure approval for life-extending drugs from the Dental and Pharmaceutical Benefits Agency, the New Drug Therapies Team, and others.

Petitions, letters and referrals

SPCF’s external activities culminated with the Prostate Cancer Campaign in September. But it also entailed responding to referrals for consideration, participating in media and petitions.

SPCF monitors and drives patient issues directed at central authorities, institutions, organisations and the media. We also respond regularly to referrals for consideration when new prostate cancer-related rules are introduced and write our own official communications. In 2013, we responded to the following:
- Referral for consideration: Interim report on patient power inquiry (SOU 2013:2)
- Referral for consideration: National guidelines for prostate cancer nursing
- Referral for consideration: National screening plan for prostate cancer
- Referral for consideration: National nursing program for psychosocial cancer rehabilitation

September Campaign 2013

A project team with representatives from Amgen, Bayer, the Swedish Automobile Sports Federation, Janssen, Lilly, Sanofi, the Swedish Federation of Uro-Oncology, the Swedish Urology Society and the Swedish Oncology Society prepared a basic concept for the year’s campaign that contained a record-breaking 160 activities (100 in 2012). The year’s prostate cancer campaign is probably the largest
prostate cancer event ever arranged in the Nordic countries. It is particularly gratifying that activities were arranged all over the country.

The main conference was held 10 September in Filadelfiakyrkan in Stockholm, Sweden, under the theme Who’s the boss of your prostate?
Topics included:
- The right to early detection: Active information and screening in new light
- The right to treatment without side effects: The responsibility of medical and healthcare services for incontinence and sexual dysfunction
- The right to life-extending drugs: A long awaited breakthrough – but can we afford it?

Politicians, doctors and patient representatives discussed the topics in order to highlight possibilities and find solutions that reduce mortality rates and improve the quality of life for men living with prostate cancer.

The conference attracted 600 participants (300 last year) and 21 exhibitors that arranged an information centre. Among the exhibitors were the Swedish Association of Urology Nurses, Form & Hälsa, Sinoba, ProLiv Stockholm, Kompas Kommunikation, Astellas Pharma, Sanofi, the Swedish Urology Society, Amgen, Eli Lilly, Stockholm’s Hospital, SCA Hygiene Products, Chundsell Medicals, Prostatabröderna, the clinic of the Swedish Association for Sexuality Education, MedNature, the Swedish Osteoporosis Association, Docrates Cancer Hospital, Sesam, the Swedish Automobile Sports Federation and Janssen.

The Campaign involved:
- An information desk set up outside shopping centres in Blekinge and Uppsala
- A series of lectures on the topic of prostate cancer given by physicians around the country
- Restaurant owners donated SEK 1 per sold beer and collection boxes were placed in bars in Karlstad
- Candle manifestation for the deceased in Karlstad
- Jazz and solo concert in Skellefteå
- Motorcycle cortege in Stockholm, the Distinguished Gentlemen’s Ride
- Many media activities that resulted in more than 400 press clippings and a vast number of blogs and articles in social media
- Figured in several daily newspaper supplements, including the Cancer supplement in Svenska Dagbladet, Mannens Hälsa in Svenska Dagbladet and a presentation of the program in a 12-page supplement in Metro
- Fundraising for the Swedish Prostate Cancer Foundation was organised in conjunction with several activities
- Extra material in the form of vests, beach flags and brochures were also arranged

More media activities than ever before
A larger number of media activities were arranged during the year and the Federation issued 14 press releases (four in 2012 and three in 2011). A substantial increase, in other words. All press releases are published on the website, which also provides a service to the media so they can access pictures and other information. A few of the press releases were modified for different associations, and local and regional versions were drafted and sent to the associations’ target groups. We have noticed that these press releases have generated even more articles and radio programs. The Federation subscribes to a press service that enables us to easily reach the media we want to reach.

Almedalen Week
The Prostate Cancer Campaign again attended Almedalen Week in 2013. SPCF’s board member Kent Lewén took part in several debates together with Director General Torsten Tullberg. They also took part in discussions and presented information in a tent. Torsten Sundberg wrote an article about the activities.
Four weekends at IKEA Kungens Kurva
Four activity weekends were arranged at IKEA in Kungens Kurva, Stockholm, between May and June, and then again in September. A blue tent housed the Swedish Prostate Cancer Federation, Proliv Stockholm and Prostatabröderna while the Breast Cancer Federation’s Swedish organization was in the pink tent. DatumLotteriet also took part. Visitors could see the exhibition, answer the popular quiz and take the chance to ask questions. In total, some 100,000 people visited the exhibition.

OLW donated 700,000 bags of nuts to the battle against prostate cancer
The Swedish Prostate Cancer Federation collaborated with OLW on a two-month campaign during which OLW sold some 700,000 bags of nuts under the campaign slogan “Save the nuts”. OLW also donated SEK 150,000 to the battle against prostate cancer. The campaign’s primary theme was Quality of life for all. The public was invited to take part in the Moustache-of-the-Year photo competition and participants posted pictures of themselves and their moustaches, real or fake, on Instagram. Information about the competition was published on OLW’s website and Facebook page, encouraging people to get involved and promoting the battle against prostate cancer! A winner of the week was posted as well as the final winner. The campaign launched a direct line of communication to Swedish homes – a communication channel that the Swedish Prostate Cancer Federation does not normally have access to. Information about activities for better quality of life was very popular.
Apoteksgruppen sold the new Blue Band at 166 pharmacies
SPCF collaborated with SCA to design a Blue Band pin that was sold in the Federation’s online shop and via the associations. Apoteksgruppen did an excellent job of selling Blue Band pins in pharmacies all over Sweden in November, bringing in SEK 175,227 from sales.

The Blue Moustache
In 2013 SPCF designed a new symbol, the Blue Moustache, and an Instagram account with the same name was set up. The Blue Moustache is used to generate a broader interest in prostate cancer and is used in collaborations to communicate with people interested in men – fashion – food – sports while supporting the fight to beat prostate cancer. During the year, an agreement was signed with the Swedish Automobile Sports Association to arrange a fundraising during the Safari Rally and the Stockholm-based race, Midnattsolsslopet. In December, the Federation had a rewarding collaboration with the restaurant Sturehof, which sold Blue Moustache pins in its bars, and even had lamb testicles on the menu – the profit from which went to the Swedish Prostate Cancer Foundation. Sturehof also helped us to arrange a Blue Moustache launch party to which those closely affiliated with the Federation were invited as well as the motorcycle club, Piston Cult. Media coverage of the party was good and it topped the list in Resumé’s online paper, Sydsvenskan and GP.
Roberto Vacchi & Rickard Herrey cycled for SEK 169,000
Wearing stylish cycling outfits, Roberto Vacchi and Rickard Herrey cycled 150 km in the Halvättern bike tour to bring in SEK 169,000. Rickard Herrey says it is important to support the fight against prostate cancer. This was the second year that Roberto Vacchi took the initiative to complete the tour to raise money for the Federation’s foundation. In addition to more money for research, the event helped highlight the battle against prostate cancer.

If Stockholm – New balls please!
For the second consecutive year If, the main sponsor for Stockholm Open, arranged a competition within the competition in 2013. If donated SEK 200 to the Swedish Prostate Cancer Foundation for every ace in the competition. Given that between 30 and 40 aces are served in a match, the result was a great deal of awareness and SEK 72,000 to the Foundation.

Motorcycle cortege through Stockholm
The last weekend of September fourty fancy-dressed men rode their motorcycles through the streets of Stockholm to raise money for the Swedish Prostate Cancer Foundation. At both the start and finish line the Swedish Prostate Cancer Federation had pitched tents to sell the Blue Band and hand out information leaflets. Called the Distinguished Gentleman’s Ride, the cortege will be repeated in 2014.
Safari Rally
The world’s most gruelling rally, the East African Safari Rally, took place 21–29 November. Eight Swedish cars were at the starting line and six were part of the Race4Health charity project that participated to raise money for select charities, one of which was the Swedish Prostate Cancer Federation. The Race4Health team boasted six of Sweden’s best rally drivers and they drove newly renovated Porch 911s in hot colours. The pink Porch with the Prostate Cancer Federation’s logotype was driven by David von Schinkel, initiator of the Race4Health project. Donations will continue to be collected after the rally and one year forward, wrapping with a ceremony to tally the figures at a gala event in Stockholm in November 2014.

1.6 Million Club’s calendar to the Swedish Prostate Cancer
Every year, Alexandra Charles and her 1.6 Million Club publish a calendar, the proceeds of which go to charity. The 2014 calendar was released at a press conference in November and it was revealed that half of the profits would be donated to the Swedish Prostate Cancer Foundation. Björn and Pernilla Skifs, Babben Larsson, Alexandra Charles and Carl Jan Granqvist, Pernilla Parszyk and Carina Perenkranz, Kattis Ahlström, Anna Maria Corazza Bildt, Helena Bergström, Maria Montazami, Ernst and Ulla Kirchsteiger, Barbro Ehnbom and Karin Ehnbom Palmqvist, Margot Wallström, Tommy Körberg, Mark Levengood, Eva Bojner Horwitz and Töres Theorell are portrayed in the calendar.

5. SUPPORT PATIENT ASSOCIATIONS
Rising number of members
The Swedish Prostate Cancer Federation is Europe’s largest prostate cancer organisation and our numbers continue to increase. The Board’s target of 8,000 members in 2013 was surpassed in January when figures reached 8,228 members. At the close of 2013, the Federation had 8,823 members,
marking a 7% increase. The associations that reported the greatest increase were Prostate Cancer Association Viktor with an increase of 45%, Betula Prostate Cancer Association with 23% and Jämtgubben at 22%. Five associations reported declining figures.

Membership recruitment
There is potential to recruit members. Of the 85,000 men in Sweden living with a prostate cancer diagnosis, only 8,823 are members – 10% in other words. SPCF has supported the associations in their membership recruitment efforts. The most important instrument is the new website launched in 2013 where membership benefits are published.

Advice
SPCF has advised the associations in how to write or change the charter, the rights of association, how to add logotypes to websites, and more.

Associations' registry system
Krister Gerdin, who first purchased the registry system, has developed and administered the associations’ registry system in a commendable way over the years. In June, Krister handed over the register to the secretariat and Board member Jan-Eriksson Nilsson was tasked with entering the associations in the associations’ registry system. Administrative assistant Annette Söderberg handles the day-to-day operation of the system. Jan-Erik Nilson contacted all the associations during the year and only one association remains to be entered in the system, a measure that will be rectified in the spring of 2014.

LYFTET training
A two-day training session about how to become a better patient representative was given in the patient associations in the spring. Some 60 members participated in total. The training session was arranged because it is increasingly common that authorities and organisations want patient representatives and this course was intended to improve their knowledge. The first round of three meetings in Uppsala, Umeå and Helsingborg addressed the organisation, governance and actors in the medical care system. The second round in Örebro focused on the disease prostate cancer and medical care. Vice-Chairman Calle Waller and Director General Torsten Tullberg coordinated. One of the participants was Marike Laliberté from Sanofi, which commendably contributed to financing the training sessions. Calle Waller was responsible for the course structure and execution.

Day 1: About the organisation and governance in medical care system and the role of patient representative
8 April Uppsala, 9 April Umeå and 10 April Helsingborg

Day 2: About the disease and treatment
6 May Örebro, 7 May Helsingborg and 8 May Sundsvall

The role of patient representative course
In collaboration with other cancer federations – Cancer Federations in Collaboration – a proposal was sent to the government for competence development funding for patient representatives in RCC’s nursing teams. A grant of SEK 800,000 was allocated and, as a first step, used for a two-day course for some 90 patient representatives, 12 of whom were from SPCF. The course will be followed up with in-depth courses in the spring of 2014. Calle Wall is responsible in collaboration with RCC.

Associations’ websites
The Federation is developing an improved and simplified model of its website which will be offered to the associations at a very low cost. A workshop was held on 21 November for some 20 people from a dozen associations. They agreed on how the Federation’s model for the patient associations’ website should be designed. A steering committee headed by Jan Erik Nilsson was formed.
Associations’ login on the Federations’ website
A special login for those active in the associations has been added to the Federations’ website. More internal information from the Federation can be found there as a complement to the official pages, including an organisation plan, minutes of meetings, certain steering documents, practical guidelines, a visual identity manual with logotypes, relevant forms and the Federation’s newsletter.

Regional meetings – for the exchange of experiences of patient associations
During the spring, well-attended regional meetings were held that included information from the Federation, a presentation of the new website launched in 2013, and a popular exchange of experiences among the associations.
Regional meeting in Helsingborg 23 January (about 30 participants)
Regional meeting in Örebro 5 February (about 20 participants)
Regional meeting in Vimmerby 3 April (about 30 participants)

Spreading material to associations
SPCF acquired beach flags that have been sent to the regions, as well as brochures and orange-coloured vests. We also have an online shop where we offer information kits. The associations have their own log in to the shop.

Visual identity manual
With the help of Art Director Jörgen Gedeon of Gedeon Design, the Federation has prepared a detailed visual identity manual. The manual contains guidelines for the associations, recommendations for colours and fonts, as well as logotypes that can be downloaded.

6. CONTRIBUTE TO R&D ACTIVITIES

90 account and control by the Swedish Fundraising Control
The Swedish Prostate Cancer Federation has a 90 account. This account is monitored by the Swedish Fundraising Control which is a non-profit organisation that approves and monitors all 90 accounts. They annually check all organisations that have a 90 account and make sure that all fundraising activities maintain a high level of quality. The purpose is to guarantee that fundraising is done in a responsible manner.

The Swedish Prostate Cancer Federation complies with Code of Quality
The Volunteer Organisation’s Fundraising Counsel strives to enhance the general public’s confidence for the fundraising sector by working for ethical and professional fundraising. The Swedish Prostate Cancer Federation complies with its Code of Quality.

The Swedish Prostate Cancer Foundation
The Swedish Prostate Cancer Foundation aims to support Swedish prostate cancer research, improve the skills of medical service providers in Swedish prostate cancer nursing and various patient representatives, as well as carry out activities to influence public opinion in the fight against prostate cancer. The Annual Assembly of the Federation decided in 2013 to revise the Foundation’s steering document.
- Policy: The Swedish Prostate Cancer Foundation (adopted by the Annual Assembly)
- Rules of procedure. The Swedish Prostate Cancer Foundation (adopted by the Annual Assembly)
- PM application and decision: The Swedish Prostate Cancer Foundation (adopted by the Board)

The Foundation allocated funds for the first time in 2011 for a total of SEK 806,000. In 2012, the amount rose 55% for a total of SEK 1,775,000. The previous year’s upward trend continued in 2013 and a total of SEK 2,254,000 – or an increase of 21% – was paid out. The Board of the Federation
intends to continue to increase allocations from the Foundation. In regards to the Foundation, see Note 9. Because several research projects run for many years, funds are allocated over several years.

**Research grants 2013**

Research grants in the amount of SEK 1,057,000 were made in 2013 (2012: SEK 1,050,000 and 2011: SEK 550,000).

1. **Per Fransson, docent, lecturer, registered nurse, Department of Nursing, Umeå University**
   SEK 100,000 to evaluate how satisfied men who have prostate cancer are with their cancer treatment and study patient satisfaction among men who have prostate cancer. The assignment involves a scientific analysis of the Prostate Cancer Federation’s survey from 2012 comprised of 3,513 questionnaires.

2. **Andreas Thorstenson, senior physician of Urology, Department of Molecular Medicine and Surgery Karolinska Institutet, SEK 207,000 for studies of embolism risks related to different prostate cancer operations and hip joint operations, as well as studies on how these risks are affected by different types of endocrine therapy and socio-economic status.**

3. **Enrique Castellanos, registered physician at Karolinska University Hospital, Radiumhemmet Stockholm**
   SEK 350,000 for the reduction of side effects and treatment period with four-dimensional radiotherapy (4DRT) for patients receiving high-dose radium treatment of prostate cancer. A student-initiated Phase 2 study.

4. **Ingela Franck Lissbrant, specialist, Medical Doctor**
   and co-applicants: Marie Hjelm Eriksson, Per Stattin, Magnus Törnblom and Jan-Erik Damber. SEK 400,000 for a pilot project in which registration of relevant variables in the treatment of men with CRPC are studied. Registration of the treatment solution, cytostatic hormones, isotopes and external radiation treatment in order to evaluate and optimize treatment indications, optimal timing as well as regional differences.

**Scholarships**

In 2013, scholarships for the amount of SEK 314,573 were approved. (In 2011, SEK 121,000 was approved for scholarships and SEK 34,000 in 2012.)

1. Registered nurse Birgitta Magnusson, Urology Clinic at Karlstad Central Hospital
2. Registered nurse Bodil Westman, Urology Radiumhemmet, process leader prostate cancer RCC Stockholm Gotland
3. Registered nurse Eva Hellberg, Urotherapy Clinic at Karlstad Central Hospital
4. Registered physician and MD Sigrid Carlsson
5. Larmpatrullen in Halmstad with 14 assistant nurses
6. Urotherapist, registered nurse Katarina Gunséus, Urology Department Surgical Centre Norrland’s University Hospital
7. Registered physician Ulla Steen-Zupanc, Director for the Department of Rehabilitation Medicine at the Red Cross Hospital in Solna. Scholarship holders from the urology team at Södertälje Hospital to participate in the 29th Annual EAU Congress, European Association of Urology, 11-15 April in Stockholm.
8. Margareta “Meta” Gylin stoma therapist and uro therapist
9. Katarina Eriksson, nurse
10. Annelie Lundström, assistant nurses training, Urology basics course, STS
11. Marianne Gillblad, assistant nurses training, Urology basics course, STS
12. Yvette Karlen, assistant nurses training, Urology basics course, STS
Influencing public opinion
Influencing public opinion is becoming an increasingly important part of the Swedish Prostate Cancer Federation’s work. During the year advertisements were published in newspapers and online to influence public opinion and thereby improve awareness for the fact that prostate cancer is Sweden’s most common form of cancer and to get the public to support the battle against prostate cancer. The ultimate objective of creating public opinion is to get politicians to prioritise efforts for better examination and treatment methods in prostate cancer care. Our activities have led to a greater awareness of prostate cancer and more people are talking about prostate cancer. In 2013, the Board decided on activities to influence public opinion from the Foundation in the amount of SEK 890,000 (SEK 691,000 in 2012).

Present situation
The Board forecasts that the Foundation will continue to increase its grants over the next few years. Extensive public opinion-oriented initiatives were carried out in 2013. The value of these initiatives stretches through all of 2014 because more and more people are now talking about prostate cancer. Our focus will be to increase grants to research and cut back on allocations directed at influencing public opinion. In total, however, grants from the Foundation will increase. The Federation now has a well functioning website, making it easier to make donations. The Federation will encourage various external parties to do fundraising and DatumLotteriet will continue to play a central role.

The Swedish Prostate Cancer Federation’s Research Council
SPCF’s Research Council is responsible for selecting and improving the quality of the Federation’s research grants. In 2013, the members of the Research Council included:

Alf Carlsson, SPCF Chairman

- Kerstin Åslund, SPCF Board member, Urologist, chief physician at Sundsvall Hospital

- Yvonne Brandberg, Psychologist, professor of Nursing Science specialising in Oncology, researcher in Psycho-oncology at Karolinska Institutet
- Lars Henningsohn, docent, chief physician at the Department of Urology at Karolinska University Hospital, chairman of the Swedish Urological Association
- Sten Nilsson, professor of Oncology, chief physician at Radiumhemmet at Karolinska University
- Torsten Tullberg, secretary

Scholarship Committee
The members of the Scholarship Committee in 2013 were:
- Alf Carlsson, SPCF Chairman
- Kerstin Åslund, SPCF Board member, Urologist, chief physician at Sundsvall’s Hospital
- Torsten Tullberg, secretary

7. ELECTED OFFICIALS AND ASSOCIATIONS

The Swedish Prostate Cancer Federation’s Board of Directors
The Swedish Prostate Cancer Federation’s Board of Directors was made up of the following members in 2013:

Full members: Alf Carlsson, Chairman of the Federation 2013–2014
Calle Waller, Vice-Chairman 2013–2014
Lars Göran Almeby 2013
Kjell Lindblom 2013
Lennart Lindow 2013–2014
Kerstin Aslund 2013

Substitute members: Christer Peterson 2013
Jan-Erik Nilsson 2013

Associated members: Torsten Sundberg

Torsten Tullberg served as the Board’s secretary.

The Federation’s Board convened seven times in 2013.
The Rules of Procedure of the Board was updated last year.
Remuneration to Board members: SEK 46,481 (for loss of income)

Auditors
Lars Lundberg, authorised public accountant, Revisionsbyrån Lundberg & Co AB, Sollentuna 2013-2014
Hans Lindén, Uppsala 2013
Leif Dellmo, Växjö 2014

Replacement
Erik Emilsson, authorised public accountant 2013–2014

Nominations Committee
Jan Cederhus Näckrosbröderna, Sörmland 2013–2014
Regional Directors
The following people were appointed Regional Directors in 2013:
Northern Region: Lennart Lindow 2013
Uppsala Örebro Region: Kjell Lindblom 2013
Stockholm and Gotland Region: Torsten Sundberg 2013
Eastern Region: Krister Gerdin 2013
Western Region: Christer Peterson 2013
Southern Region: Kent Lewén 2013

Remuneration Committee
Leif Dellmo, convening
Lars-Börje Hellberg
Bengt Göran Roskvist
Torsten Tullberg, secretary

Other assignments
Krister Gerdin, responsible for the association’s registry system through June 2013

Finance Committee
Alf Carlsson, convening
Kjell Lindblom
Torsten Tullberg

Website team
A reference group set up to make it easy for patient associations to link their websites to
Föreningssupport (the support team) and the Federation’s website.
Jan-Erik Nilsson, Chairman
Rune Divander, SPCF in the County of Uppsala
Alf Stenlund, ProPsa Norrsken
B-G Roskvist, Pro Vitae
Håkan Karlsson, Pro Vitae

Patient associations
In 2013, the Swedish Prostate Cancer Federation was made up of the following 26 patient
associations:
The number of members presented in the table below is as of 31 December 2013.

<table>
<thead>
<tr>
<th>County</th>
<th>Association</th>
<th>Members 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blekinge län:</td>
<td>Prostatacancerföreningen Viktor</td>
<td>504</td>
</tr>
<tr>
<td>Dalarnas län:</td>
<td>ProLiv Dalarna</td>
<td>332</td>
</tr>
<tr>
<td>Gotlands län:</td>
<td>Gotlands Prostataförening</td>
<td>39</td>
</tr>
<tr>
<td>Gävleborgs län:</td>
<td>Prostataföreningen Gävleborg</td>
<td>197</td>
</tr>
<tr>
<td>Hallands län:</td>
<td>CaPriN</td>
<td>279</td>
</tr>
<tr>
<td>Jämtlands län:</td>
<td>Jämtgubben</td>
<td>1139</td>
</tr>
<tr>
<td>Jönköping län:</td>
<td>ProLiv Jönköping</td>
<td>235</td>
</tr>
<tr>
<td>Kalmar län:</td>
<td>ProClub Möre, Kalmar</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td>ProTjust, Västervik</td>
<td>179</td>
</tr>
<tr>
<td>Kronobergs län:</td>
<td>ProLiv Kronoberg</td>
<td>387</td>
</tr>
</tbody>
</table>
8. ANNUAL ASSEMBLY AND GOVERANCE OF THE FEDERATION

Annual Assembly
On 17–18 April the Annual Assembly was held onboard Viking Lines’ m/s Cinderella. Torsten Sundberg was responsible for organising the excellent arrangements. Former Secretariat Director Esbjörn Melin presided as chairman. The agenda was extensive and included reviewing the regulations, the standard association regulations, the Policy for the Swedish Prostate Cancer Foundation, and the Rules of Procedure for the Swedish Prostate Cancer Foundation. Discussions were lively, particularly concerning the six proposals. Elections were held, financial issues for 2011 and 2012 were approved, the Board was discharged from liability for the financial year, the budget for 2013-2014 was adopted and a decision was taken regarding the business plan for 2013 and 2014.

Honorary award
The Swedish Prostate Cancer Federation’s Honorary Award for 2012 was presented to Anders Gyhlenius in recognition of his dedication to raising awareness about prostate cancer and his

* ProÖst figures as of 1 January 2013

No. of members January 2010: 6,756  
No. of members January 2011: 6,728  
No. of members January 2012: 7,595  
No. of members January 2013: 8,228  
No. of members January 2014: 8,823

- No. of friends and relatives groups: 6  
- No. of associations whose numbers grew in 2013: 20  
- No. of associations whose numbers declined in 2013: 5
enthusiasm for life. The jury found that “Anders has drawn a great deal of attention to prostate cancer and helped to spread awareness about the disease. Candidly and openly, he has talked about the disease and the right to equal care on the radio, television and in the press. He has held lectures for both the care sector and for pharmaceutical companies. By going into detail he has contributed to enhancing awareness about how a patient with metastatic prostate cancer feels. But Anders has also demonstrated that it is possible to find joy and a passion for life while living with prostate cancer.” The awards ceremony was held 6 March at IKEA in Kungens Kurva where Anders works. Anders Gyhlenius was also recognised at the Annual Assembly where he held a highly appreciated speech.

The Federation’s Board of Directors
In 2013, the Federation’s Board of Directors convened in February, April (two meetings), May, August, October, and December. The Board amended the instructions for the Board and the Director General, and evaluated the work of the Board and the Director General. The Board gave priority to preparing for and following up the Annual Assembly, as well as making sure improvements are made in the Federation’s financial steering and control. During the year, the Board implemented measures recommended by the auditors, such as preparing recommendations for a cost centre budget based on the business plan and any subsequent projects/initiatives for following up daily accounting of how Foundation funds are used, among other matters. Unfortunately, this work was delayed and the new cost centre budget will be used first in 2014. The Board continued to work on the business plan for 2014 and prepared a revised budget proposal for 2014.

During the spring of 2013, the Board drafted:
- Recommendations for amended regulations (adopted by the Assembly)
- Recommendations for standard patient association regulations (adopted by the Assembly)
Recommendations for a policy for Swedish Prostate Cancer Foundation (adopted by the Assembly)
- Recommendations for Rules of Procedure for the Swedish Prostate Cancer Foundation (adopted by the Assembly)
- Applications and decisions: the Swedish Prostate Cancer Foundation
- Structures for evaluating the work of the Board
- Amendments to the Ethnical Guidelines (minor linguistic changes)

During the autumn the Board drafted:
- Revised Rules of Procedure for the Federation’s Board of Directors
- Instructions for the Nominations Committee
- Instructions for the Director General
- Revised budget proposal for 2014
- Revised proposal for the 2014 business plan
- Rules and forms for the fundraising activities carried out by the associations towards the Swedish Prostate Cancer Foundation
- Social media strategy

9. Administration and secretariat

Improvements in administration
SPCF’s auditors stated in their 2012 audit report that it was necessary to improve the steering and control of the Federation’s finances and the Board therefore adopted measures in 2013 to improve steering and control of its finances. A cost centre budget based on the business plan was prepared and budget follow up routines were improved. As a result of these efforts, new routines will be implemented as of 2014.

Employees working at the Federation’s secretariat
The Federation has a secretariat on Barks väg in Bergshamra in Solna, Sweden. In 2013 one public information officer joined the staff which now comprises:
Torsten Tullberg, Director General
Emma Magnusson, Public Information Officer
Anette Söderberg, Administrative Assistant

Interns:
Sarah Magnusson, September 2012–January 2013
Lovisa Larsson, January–June 2013
Nathalie Saller, June–August 2013
Magnus Ekvall, August–October 2013
Frida Hanson Franchell, October–November 2013

External resources
The following consultants were contracted during the year:
Hedin Ekonomikonslut AB handled bookkeeping and the year-end report.
Art director Jörgen Gedeon, Gedeon Design, designed our graphic layout and design.
Föreningssupport handled the associations’ registry system and produced the website.
Burenstam & Partners handled management of the Federation’s assets.
10. Growing collaboration with others

The Swedish Prostate Cancer Federation has limited assets. Collaboration is a top-priority alternative to expand our operations. During the year, a variety of collaborations have helped the Federation to achieve its objectives.

Collaborations with the profession
SPCF has established collaborations with:
- the Swedish Urology Society
- the Swedish Oncology Society
- the Swedish Federation of Uro-Oncology
The Federation has had several articles published in the Swedish journals *Svensk urologi* and *Svensk onkologi*.

SPCF and the Cancer Foundation
SPCF and the Cancer Foundation have collaborated closely throughout the year.

Cooperation projects
In line with the Ethical Rules of the Pharmaceutical Industry, all cooperation projects that SPCF has had throughout the year with pharmaceutical companies are reported below:

*The September Campaign (Septemberkampanjen)*
- Amgen
- Bayer
- Janssen
- Lilly
- Sanofi

*The Blue Moustache (Blå mustaschen)*
- Amgen

*The Blue Band (Blå bandet)*
- SCA

*The Nordic survey*
- Astellas

Other partnership agreements
- A number of pharmaceutical companies have advertised in *Prostatanytt*
- OLW, Save the nuts, Instagram competition, moustache competition
- Swedish Automobile Sports Federation, with activities including the Safari Rally and the *Midnattsolsloppet*
- Insurance company, IF, during Stockholm Open
- Apoteksgruppen, sold Blue Band pins at more than 160 pharmacies in November
- A number of companies that sell the Blue Moustache pins

Other national collaborations
Below are the authorities, organisations and companies that the SPCF collaborates with in some way or that influence the Federation’s operations.

National guidelines for prostate cancer treatment
The Federation presented its views regarding the National Board of Health and Welfare’s proposal for national guidelines for prostate cancer treatment.
National nursing program
During the year, the task began of preparing a National Nursing Program for Prostate Cancer, intended as a complement to the more fundamental National Guidelines. Ola Bratt is heading up the project. Calle Waller is the Federation’s representative on the team with Kent Lewén as his replacement.

Cancer Federations in Collaboration
SPCF has together with other cancer patient federations formed an informal network for driving joint issues. Calle Waller, Vice-Chairman of SPCF acted as the coordinator in 2012 and 2013. A number of meetings were arranged and Calle participated in one in January that addressed collaborating on an article to be published in the journal *Dagens Medicin*, and the planning and execution of a visit to the Ministry of Health and Social Affairs.

RCC
RCC is a five-year project to develop and improve cancer care in Sweden. An extensive collaboration has evolved in just a short time at both national and regional levels. One RCC sub-project involves drafting national guidelines for nursing in different fields, including prostate cancer. Calle Waller is the Federation’s representative, with Kent Lewén as replacement. Through the Cancer Federations in Collaboration, the Federation has ongoing discussions with RCC about how it can play a more active role in the RCC project. At a regional level some 20 SPCF representatives are involved in various teams, particularly patient counselling and nursing program teams. SPCF supports and coordinates input via the RCC team, of which Lars-Olof Strandberg, Karl-Erik Gustavsson, Krister Gerdin, Olof Söderlind, Stig Lindahl and Thorbjörn Lindberg are members with Calle Waller as convening.

The Swedish Disability Federation
SPCF is a member of the Swedish Disability Federation and attended several meetings on the topic Responsible Health and Medical Care.

Socialstyrelsen

Sveriges kommuner och landsting (SKL)
Samverkansorganisation för bl.a. alla landsting och regioner. Genomför årligen jämförelser avseende delar av prostatacancersjukvården. Tar policybeslut om sjukvårdsbudsjutningsnivåns prioriteringar, samarbetet och utvecklingen. Calle Waller har deltagit på möte med SKL i januari och i april samt i oktober och november angående bland annat väntetider i cancervården och kvalitetsregister.

Svensk Insamlingskontroll
Beviljar och övar tillsyn avseende 90-konton.
KFO
Arbetsgivarorganisation för den ideella sektorn.

FRII
Frivilligorganisationernas Insamlingsråd som ger utbildning och erfarenhetsutbyte med andra insamlingsorganisationer.

Apotek
Förändringen på apoteksområdet följs av PCF avseende tillgänglighet, service, öppettider mm.

Tandvårds- och läkemedelsförmånsverket (TLV)
Beslutar bl.a. om vilka läkemedel som ska ingå i läkemedelsförmånen. Calle Waller deltog på TLV-konferens i januari och i april.

Läkemedelsindustriföreningen
Svarar bl.a. för läkemedelsbranschens etiska regelverk som reviderats under året.

Läkemedelsföretag
Viktiga samarbetspartners för ekonomiskt stöd till föreningarna och PCF. Calle Waller och Torsten Tullberg har under året haft kontinuerlig kontakt med inblandade läkemedelsföretag.

Nationella prostatacancerregistret (NPCR)
Följer och dokumenterar utvecklingen av prostatacancer och behandling, resultat och överlevnad. Calle Waller är förbundets representant i styrgruppen och deltog på ett tvådagarsmöte i Sigtuna i januari samt i styrgruppssmöte i september.

Nordic collaboration
SPCF meets its Nordic sister organisations every year to exchange experiences.

Nordic Conference in Helsinki in June
Calle Waller, Torsten Tullberg and Stig Lindahl took part in a Nordic conference in Helsinki between 6 and 7 June.

European collaboration

Europa Uomo (EUomo)
SPCF is part of the European affiliation of patient associations in the field of prostate cancer. The Board has appointed Calle Waller as the Federation’s international spokesman. Calle attended the EUomo-Assembly in Antwerp, Belgium, 30 May–1 June and the Prostate Cancer World Congress in Marseille, France, 12–15 June.

11. MISCELLANEOUS

Guidelines for asset management
SPCF contracted Burenstam & Partners to provide financial counselling and asset management services in 2013. The Board adopted the revised guidelines for the Federation’s asset management.
12. FINANCIAL SITUATION OF THE FEDERATION

Government grants
The Federation received a grant from the National Board of Health and Welfare in the amount of SEK 2,084,000 (SEK 2,005,000 in 2012) which is the base for the Federation’s financing. The size of the grant is significantly determined by the number of paying members in the Prostate Cancer Associations.

90 account
The Swedish Prostate Cancer Federation was assigned what is called a ‘90 account’ for public fundraising and is therefore monitored by the Swedish Fundraising Control which conducts yearly checks of all 90-account holders to ensure that fundraising activities maintain a high level of quality. This control certifies that fundraising has been done in a responsible manner. In 2013, fundraising via our 90 accounts gave SEK 1,609,752 (SEK 1,684,564 in 2012).

DatumLotteriet
DatumLotteriet has grown during the year and contributions to SPCF in 2013 amounted to SEK 2,035,000 (SEK 1,230,000 in 2012). Of this, SEK 815,000 was allocated to the Foundation. (Last year, the entire contribution from DatumLotteriet, SEK 1,230,000, was transferred to the Foundation).

The Swedish Prostate Cancer Foundation
The Swedish Prostate Cancer Foundation had SEK 5,180,000 in 2013. Last year’s opening balance was SEK 4,355,000 and a funds transfer of SEK 825,000 was made. In regards to revenue to the Foundation, fundraising revenue has averaged SEK 1 million per year over the past years. At SEK 500,050, donations from companies were somewhat lower in 2013 (SEK 645,000 in 2012). In 2013, SEK 314,000 was raised through the sale of the Blue Band and Blue Moustaches and DatumLotteriet generated SEK 815,000. In all, revenue to the Foundation totalled SEK 2,817,183 (SEK 3,052,000 in 2012). Dividends from the Foundation rose during the year. For more details, see pages 13–15 and Note 9.

Other revenue
Five pharmaceutical companies donated SEK 100,000 each in 2013 towards the Prostate Cancer Campaign.

Returns on the Federation’s liquid assets
In 2013, the Federation managed liquid assets in the range of SEK 6.3 million. Returns for 2013 reached to 2.9% (3% last year), including an unrealised appreciation in value of SEK 95,000 for an investment portfolio.

Deficit for the year
The Federation reports a deficit of SEK 81,339 for 2013 (a surplus of SEK 555,033 in 2012).

The Swedish Prostate Cancer Federation aims for a zero deficit or a minor surplus. Last year’s Federation activities were very extensive and donations from the public and companies were lower than anticipated in December.

Alongside the funds appropriated to the Swedish Prostate Cancer Foundation, SEK 2,817 183 (see Note 9), an additional SEK 95,331 has been used for Foundation-related purposes. This amount is taken from funds set aside in previous years for Foundation-related purposes in the Federation’s assets. Since the Foundation’s deficit was larger than the Federation’s deficit, the Federation’s retained unrestricted capital can be adjusted for the difference, or SEK 13,992.
Assets at the close of the year for the Swedish Prostate Cancer Federation totalled SEK 5,877,211, of which SEK 5,180,000 is for the Swedish Prostate Cancer Foundation-related purposes. The financial results and situation of the Federation is otherwise reported in the following Income Statement and Balance Sheet, as well as the Supplementary Disclosure Notes.