2013 Annual Report

Cesta domů, a hospice civic association

INTRODUCTION

In 2013, we helped 134 patients (not only seniors, as one third of our patients were of working age and many were parents of small children) through the last days and weeks and their lives. This means that our doctors and nurses paid these patients about 3,000 visits (almost 400 hundred of them during nights or weekends, outside GPs office hours); our social workers, psychotherapists and chaplain visited the patients 300 times; social workers in our advisory centre undertook 2,000 personal, telephone, or even online consultations; our respite assistants made 2,000 visits; and we rented 600 aids to our patients.

In other words, people taking direct care of our patients accomplished an impressive volume of work last year, as the numbers above are the highest in our history. They deserve my thanks and recognition not only for all their work; being the General Director of Cesta domů may be considered a fulfilled "director" dream, considering the great atmosphere in the organization, which means a lot to me.

Given that we do not get a single penny from our patients' health insurance, we would not survive without the support of many and many natural persons and legal entities. Last year, the total amount of their donations was incredible; the donations more than doubled in comparison to the previous year and amounted to almost CZK 12,000,000. This allowed us to further develop our direct care services, increase the number of our medical and counselling staff, increase the immediate capacity for patients in care, and pay for emergency on-call coverage from our doctors. For the first time, we were able to ensure a continuous operation of our medical and advisory centre teams this Christmas. Hats off to all our donors, who have been making this possible for us and especially for our patients. I would like to add that more than half of our budget has been covered by a large number of individual gifts, often in the order of several hundred CZK; the rest is covered by grants and donations. Our medical team was joined by one male nurse and one female doctor (overall, there are three staff and six external physicians in our team). Our head physician obtained her license of a senior consultant, and we therefore are the first purely mobile palliative care facility with a senior consultant in the Czech Republic. Moreover, both our patients and their families can now use the extended services of the psychotherapist, an important team member in all direct care professions.

As in 2012, we managed to keep the amount of CZK 200 a day as the participation of the patients or their families. The cost of one day of treatment of one patient in our care was CZK 1,900; we could cover it only thanks to the above mentioned gifts and donations, and also a systematic work with grant resources. For comparison, the cost of one day in hospital care is around CZK 3,500 for one bed in a standard room in Prague; as for intensive care, which would be needed by almost one third of our patients in the last days of their lives, the

price is around CZK 15,000 a day. That is why we tried our best to persuade our government that mobile palliative care should be part of the Czech health insurance system; unfortunately, we did not succeed again. This absurd situation has been here for quite a while; home palliative care may be one of the cheapest and strongly preferred options of care for dying patients, but our health insurance companies still refuse to pay for it. On the other hand, they pay for hospital care, which is in all cases more expensive and definitely not better than home palliative care.

At the beginning of 2013, we were getting ready to move into new premises that allowed us to have all our direct care teams and administration workers under one roof. The new premises were found in Boleslavská street, thanks to the helpful attitude of the town hall of the Prague 3 Municipal District. We had to perform a demanding restoration, especially of the current Medical Equipment Rental. We managed to prepare and plan the moving successfully, so there was no need to interrupt our services. The new offices are light and spacious – nice and functional facilities for us. Many volunteers helped us to move; most of the equipment came as donations. As the administration department moved, the original premises in Bubenská street could be opened to public. In the second half of 2013, several exhibitions and lectures took place there; moreover, the possibilities of our Charity shop and information point have been extended.

In 2013, we also started to work on our palliative centre vision, thanks to the generous support of Mr. Lubomír K. This centre is supposed to be not only a new facility for services we offer nowadays, but also for other palliative care activities, especially in the field of education and research, in the Czech Republic and other Middle and Eastern Europe countries. For this purpose, we have gained the support of five foreign universities; at the end of the year, we also entered into a purchase agreement for a building under construction next to the Sue Ryder Home in Michle, a district of Prague 4.

Last year, we also fully launched a bedside documentation system – the records are made on touch tablets right in our patients' homes. This system suits our never ending work the best; it enables real-time and safe sharing of up-to-date information between doctors and nurses on the development of our patients' health state. At the end of 2013, we developed our own interface for secure entries in the documentation designed specifically for tablets and smart phones; we plan to use this interface not only for health team members, but also for respite services staff and other employees working in the field.

Many of these successes have been achieved thanks to almost incredible coincidences; others have been the result of the long-time leadership of Martina Špinková, the previous General Director of Cesta Domů. And none of what I have described above would have happened if it were not for all the excellent people working with us or supporting our work. I would like to thank all those people for the year 2013.

Marek Uhlíř



Home Care Hospice doctor with Mr. Bohuslav F.

REGISTERED OFFICE AND CONTACTS

Hospice Civic Association Cesta Domů

info@cestadomu.cz / www.cestadomu.cz / Identification Number: 265 28 843

Health Facility, Advisory Center, Patient Intake Office and Respite Services of Cesta

Boleslavská 16, Praha 3 / Phone 283 850 949 / Mobile 775 166 863

Medical Equipment Rental

Boleslavská 12, Praha 3 / Mobile 775 556 925

Library and offices

Boleslavská 16, Praha 3 / Phone 266 712 610

Registered Office, Charity Shop

Bubenská 3, Praha 7, 170 00 / Mobile 776 556 931

Bank connection:

Account number: 2800193970/2010, Fio banka, a.s., V Celnici 1028/10, Praha 1

If you want to send us a one-time gift, use variable symbol 357.

Thank you very much.

Websites of Cesta domů:

www.cestadomu.cz – presentation of the association and its services www.facebook.com/cestadomu www.umirani.cz – information, discussion and advisory portal vzpominky.nezavirejteoci.cz – virtual memorial site www.pod-strechou.cz – Home with hospice care eshop.cestadomu.cz – Charity shop of Cesta domů knihovna.cestadomu.cz – Library of Cesta domů

HOSPICE CIVIC ASSOCIATION CESTA DOMŮ AND ITS MISSION

Cesta domů is a non-profit organization; its mobile hospice services enable home care for terminally ill and dying patients and offer support to their families.

The organization also tries to contribute to social and legislative changes that are necessary for improving care for dying people. Cesta domů offers educational activities, runs several web portals, and has its own publishing house and a specialized library.

All its employees believe that dying is an important part of human life, and have been continuously promoting this message in public.

The Hospice civic association Cesta domů was founded in 2001. Currently, there is an undergoing transformation of our association into the registered institute according to the New Czech Civil Code.

ACTIVITIES OF CESTA DOMŮ IN 2013 – DIRECT CARE

Home Care Hospice Cesta domů

Cesta domů provides a system of interrelated services that aim to support patients, their families and carers who find themselves in the difficult situation caused by an incurable disease with a short prognosis. We offer mobile specialized palliative care, which is characterized by multidisciplinarity – people with various professions and from different teams cooperate to fulfil one common aim: to think of ill people not only from the medical point of view, but in the whole context of their personality and social relationships. As for our organization, help and support for dying people and their families are provided by the following six employee teams: medical team, advisory centre, respite services, support services, volunteers, and medical equipment rental. All these services are provided under the

leadership of Martina Pojarová.

Medical Team

Our medical team consisting of three staff and six external physicians and seven nurses has been led by Irena Závadová, the senior consultant, and Anna Krutská, the head nurse. Our Home Care Hospice offers a 24/7 specialized palliative care provided lege artis; the purpose is to maintain the best possible quality of our patients' lives according to their preferences when all curative treatment possibilities have been exhausted. In 2013, most of our patients had at average 32 days of life left at the time of admission to our facility; more than one half of them died within the next fifteen days.

In 2013, we provided this care to more patients than in any of the previous years; there were even patients suffering from very complicated symptoms, or patients whose health state called for highly specialized methods. We provided home care to 134 patients; compared to 2012, we were able to take care of 15 patients more, but we still could help not even one half of 298 dying people, who applied for admission. There is a growing demand for home hospices in the Czech Republic, but it still faces the reluctance of the public health system that rejects to understand these services as standard ones. Our medical team performed 2,976 visits to our patients; the average duration of one visit was 72 minutes. It is exactly this willingness of ours to pay as much attention to the ill as needed that people value most about our work.

As in the past years, over 80 % of our patients had oncologic diagnoses. A quarter of our patients belonged to the economically active age group. The general partner of our medical team has been Avast.

Professional Social Consulting

The Cesta domů advisory centre, managed by Olga Stránská, is a registered social service that provides comprehensive professional personal, phone and online consulting services to dying people, to caregivers attending to the terminally ill, to the bereaved and to all other people who want to learn about the topic. The centre employees assist the inquirers in their new situation; they help them to choose an appropriate service or facility, to obtain necessary contact information and to learn the basic nursing procedures needed when taking care of a seriously ill person. The centre employees also explain the principles of home care hospice services and mediate the first contact before starting hospice care.

In 2013 the centre employed 5 consultants who completed 1756 personal and phone interviews -19% more than in the previous year. Our online consulting centre provided its services to people from all around the Czech Republic who could consult a doctor, a social worker or a psychotherapist. Last year, these services were used by 349 people -26% more than in 2012. The published answers are, however, not only read by the one who asked the question.

We believe that our consulting services not only contributed to spreading of knowledge of the possible ways of helping dying people and the bereaved among the interested public from all around the Czech Republic and to dispelling of some myths about death and dying, but also helped many families with taking care of their loved ones.



Our volunteer Helena helping at the Cesta domů Ball

Support Services

Our psychosocial workers, psychotherapists and chaplain provide a wide range of support services to address the psychological, social and emotional facets of terminal illnesses. If a patient asks for it, they work in the field, too.

The psychosocial worker visited clients 172 times; our psychotherapists undertook 27 consultations with clients; and the presence of the chaplain was requested 13 times, both by our clients and their families.

Our support services team also largely supports the bereaved who can either use either personal consultations, or attend the *Podvečer* club meetings. The *Podvečer* club is a direct follow-up of the Home Care Hospice services and gives time and space to the bereaved who are coping with the loss of their beloved ones. It is opened to all people who have suffered such a loss, not only to the families that have been visited by our medical team.

Respite Services

Our Respite Services team, managed by Karolína Pochmanová, consists of eight assistants. Gradually more and more popular and valued among our clients, the Respite Services team members may take care of terminally ill or dying people for an agreed period of time, so that their carers have enough time for themselves or their jobs, and can relax or sleep. These social services are registered.

In 2013, these services were used by 42 families that were visited 2,060 times by our assistants; compared to 2012, the number of clients using respite services almost doubled, and the total number of performed visits was even four times higher this year. The most usual duties our respite services assistants undertook were helping the clients with dressing, eating, washing etc. Their presence often supplemented the absence of close family members and other carers. The clients therefore needed not to go to the hospital and could stay at home among their beloved ones.

Medical Equipment Rental

We provide both the families of the Home Care Hospice patients and other clients from the public with electric adjustable beds, various types of wheelchairs, active and passive antidecubitis mattresses, oxygen concentrators, linear medicine dispensers, infusion pumps, electric tub hoists, toilet chairs, walkers and other minor aids.

In 2013, 576 aids were rented to 240 clients of the Medical Equipment Rental. The Rental worked under the leadership of Pavel Krása.

Home with Hospice Care "Pod Střechou"

In spring 2013, it was one year since we and the retirement home run by the Prague 2 Municipal District had opened the Home with Hospice Care "Pod Střechou" (Home Under the Roof). During 2013, 21 people could spend last days of their lives in a dignified way thanks to this facility; these people would otherwise not be admitted to our home care program as their homes were not suitable for a daylong care. The Home with Hospice Care "Pod Střechou" is a pilot project; we have been testing the possibilities of cooperation between an inpatient hospice facility and a team of specialized mobile palliative care. The project has been revealing many and many legislative problems and barriers and we have been trying to overcome them.

Volunteers

In 2013, the work of dozens of volunteers in Cesta domů was supervised by Tereza Bímová and Olga Stránská. As in the past years, the volunteers helped the clients' families and the carers, completed the transport of aids from the rental, helped with administrative work and with organising various events for the public.

In 2013, the volunteers spent 498 hours helping in the library and in the office; 1,273 hours taking direct care of our patients in their homes or in our Home with Hospice Care; 603 hours organising and working at events for the public; 192 hours transporting aids to and from our clients (transportation of electric adjustable beds was among the most common duties); and 885 hours working in our Charity shop. In total, they spent 3,453 hours of their leisure time working for Cesta domů.

In March 2013, Adriana Skálova from the Hestia association was awarded by Křesadlo 2012 Prize for her volunteer involvement. This was for the fifth time a volunteer of Cesta domů received such a prize.

In April 2013, 14 volunteers completed their preparatory course. In October, the 11th cycle of volunteer training was launched with a total number of 19 applicants enrolled.

OUR ACTIVITIES TOWARDS THE PUBLIC

Educational activities

In 2013, we presented dozens of lectures and courses for both the general and the professional public. We consulted a project of the Czech Development Agency for establishing mobile palliative care in Kosovo. We also enabled employees of newly emerged or developing organizations for palliative care from Bohemia and Moravia to take part in ten intensive internships. Our employees lectured on many conferences. We helped to organize the world congress of the European Association for Palliative Care (EAPC) in May 2013; we got actively involved in it and succeeded with our abstracts for the scientific congress EAPC 2014 to be held in Lleida, Spain.

Therefore, we presented lectures for both the general (schools, interest groups, commented projections) and the professional public (health schools, medical faculties, clinical departments) and we established important cooperation with our partners from both the East and the West. We spent dozens of hours supporting various emerging initiatives for mobile palliative care all around the Czech Republic – we have been trying to pass our 12 year knowledge to others. Our medical staff got also actively involved in organizational and lecturing work in ELNEC (End of Life Nursing Education Consortium), an international project for education of nurses in palliative care; in 2013, we became a leading organization in nurses education.

Our senior consultant Irena Závadová became the head of the Department of Palliative Medicine at the Institute for postgraduate medical education.

Heavily supported by STEM/MARK agency, we conducted a representative research in autumn 2013, on how the Czech general and professional public sees death and dying. The results are available from http://data.umirani.cz or in the The Czech Social Science Data Archive (ČSDA) at the Institute of Sociology of the Academy of Sciences of the Czech Republic.

Cesta domů Websites

Martina Dvořáková is responsible for all websites and the Facebook profile of Cesta domů. In 2013, the websites of Cesta domů played again an important role in communication with our clients, supporters and donors. Although our websites focus on very specific topics of terminal illnesses and dying, two of them (the most read ones) had an arguable impact on 2.8 percent Czech people in 2013. The www.umirani.cz (www.dying.cz) website was accessed by 243,850 unique visitors (668 visitors a day on average); the www.cestadomu.cz website was accessed by 55,304 visitors (152 visitors a day on average).

The large website Umírání.cz (Dying.cz) has still been the main informative website for dying people and their carers in the Czech Republic. This web also runs the above mentioned online consulting centre. Its content has been gradually actualized – there are many articles and a list of educational opportunities from the field of palliative care. Currently, there are hundreds and hundreds of pages and articles in the website and it is being worked over to improve its structure.

Facebook is becoming a more and more important medium for people who want to know about our activities. We use our profile intensively; in 2013, more than 150 posts were shared, each of them influencing 1,800 people in average (the most popular post was from the 3rd of April and was read by 9,353 people). The number of our fans grown from 1,955 in 2012 to 2,947 in 2013; most of the fans are women (77%) and young people (39% of our fans is from 25 to 34 years old). Most of them are from the Czech Republic (especially from Prague and Brno), but we also have about 150 followers from Slovakia, Germany, the Great Britain, Austria, the USA, and France.

A great deal of attention was also paid to the Vzpomínky.nezavírejteoči.cz website (Memories.dontcloseyoureyes.cz) where the bereaved can share memories of their beloved ones through virtual memorials – last year, their number overreached 900. The community of people our websites help at the time of bereavement continues to increase.

In 2014, we are going to focus on improving the functionality and structure of our websites and on making the online fundraising tool kalendar.cestadomu.cz (calendar.cestadomu.cz) more effective.

Library

The Cesta domů's Library is managed by Ludmila Nohýnková; it is the only public library in the Czech Republic specialized in palliative and hospice care, dying and other related topics. It is a unique collection of books including numerous international publications, elsewhere unobtainable. In 2013, the library continued to help the professional and general public and students to find their bearings in palliative issues. The library offers and uses interlibrary lending system, thus serving the readers all over the country. We use the Clavius library software. The entries are catalogued in the Union Catalogue of the Czech Republic and the library is a member of the Medical Libraries Club.

In 2013, 182 books and 24 audio books, audiovisual media and electronic resources were acquired for a total of over CZK 79,000. We thankfully state that 139 were obtained as gifts, the remaining 135 books or other information carriers were bought.

The library contains over 3400 titles. A total of 1018 readers visited our library and borrowed 4086 books. The online catalogue was visited 954 times and a total of 11,874 enquiries for a particular publication were raised.

Publishing activities

In 2013, we focused on several new publishing activities. In cooperation with the Veselé poutnice book club, we published a successful book called *Adventní čtení* (*Readings for Advent*) – a literary advent calendar with 24 texts written by both Czech and foreign authors and illustrated by Martina Špinková.

We also created an original 2014 diary in cooperation with papelote, a stationary brand, and Alžběta Skálová, an illustrator. As in the previous years, we published our own wall calendar for 2014 with pictures taken by more or less famous photographs. We also printed new editions of several times proved information leaflets and detailed brochures for both Home Care Hospice clients and the general public. A catalogue accompanying a charity auction with reproductions of works of art was published, too.

The number of our stationary products has increased. We prepared a new edition of our successful cards for concentration game called *Každý je někdy doma* (*Everybody is at home sometimes*). The proceeds from the sale go to support the Home Care Hospice.

Charity Shop and our spaces in Bubenská street

The spaces of Cesta home in Bubenská street, Prague, managed by Tereza Špinková in 2013, were not only used for the distribution of our books, leaflets and brochures and for the charity sale, but it was also an important meeting point for people who engaged themselves in our Charity shop and its social life (exhibitions, lectures and other activities). The spaces are not only used for the Charity shop, but also as an information point, offices, and premises for the

auction and our publishing and production activities. In 2013, the Charity shop took place in many events, such as concerts, fairs, markets and festivals. It is great that we have more space for our charity second hand called JAKPAK (HOW) that has become an important part of our shop. People can bring us valuable things they do not need anymore, and we sell them. The proceeds from the sale go to support the Home Care Hospice; currently, the second hand represents the main part of the Hospice revenues. The second hand can exist especially thanks to our volunteers who work there for almost the whole day. There were also about ten openings of exhibitions, new books or CDs taking place in the premises.

Events for the public and benefices

Our traditional spring ball and autumn concert have attracted hundreds of visitors. On the autumn concert that took place on the World Hospice Day eve, played the *Traband* and *Praguematique* bands, and the tube quartet *Sila* as a guest.

In 2013, our sympathizers and supporters organized many charity events for us again – let us name at least several of them: the tradition beneficiary concert that took place in St. Markéta Church at Břevnov, Prague; an annual massage day of the Zdraví Studio; Dobrobazar in Čestlice; a multigenre festival Lacus Mortis at Vyšehrad, Prague; and many others.

There was also the third annual auction of artworks; when generous artists and willing patrons of art meet, the result is a great onetime support to the Cesta domů's activities. Many thanks for the support and encouragement that we are given every year not only by the forms of support named above.

The production of these events, publishing activities and our Charity shop were managed by Vojtěch Kozlík.

OUR PERSPECTIVES

In the end of 2013, we worked on the development vision of Cesta domů for next four years. Our goals are not small. Let us name at least several of them: We would like to double the number of people that will be able to spend last days of their lives in a dignified way thanks to our Home Care Hospice; to integrate mobile specialized care into the system of the public health insurance in the Czech Republic; to support the foundation of a new academic workplace specialized in education and research in palliative medicine within the university.

Cesta domů owns a building in Michle, Prague; thanks to the generous gift of Mr. Lubomír K. Cesta domů is going to turn this building into the Palliative centre that will be used also for undergraduate and postgraduate education of health staff and for academic research in both

national and international context. Our cooperation with the sphere of general practitioners, ambulatory specialist and clinical workplaces of Czech hospitals (even with the "superspecialized" ones) is very promising. Currently, there is an undergoing transformation of our association into the registered institute according to the New Czech Civil Code.

Thanks to our stable and actively working direct care teams, it is now clear, that (compared to the previous years) we will be able to admit even more patients to our Home Care Hospice in 2014, than we and our patients could hope.

As there is a permanent uncertainty of financing the mobile palliative care, our attention will be focused especially on an effective fundraising, on enforcing changes in the system, and on defending the concept of "good dying" in patients' own social backgrounds.

By our membership in the free group called Forum for mobile specialized palliative care, we want to contribute to experience exchange and effective cooperation among all Czech organizations that work with dying people in their homes. We also want to be good and reliable partners to the Czech Society of Palliative Medicine and the Czech Medical Association of J. E. Purkyně (ČLS JEP) and the Association of Hospice Palliative Care Providers (AHPCP).

ASSOCIATION BODIES

Association Board in 2013:

Akad. mal. Martina Špinková

Association Chair

Mgr. Václava Bratinková

Association Vice Chair

Prof. RNDr. Milan Kodíček, CSc.

Association Vice Chair

Doc. MUDr. Štěpán Špinka, Ph.D.

Association Vice Chair

RNDr. Josef Basík

Mons. ThLic. Tomáš Holub, Th.D.

Ing. Richard Kaucký

Mgr. Ondřej Krása

JUDr. Rostislav Silný

Association Board Members

Association Audit Commission:

Ing. Martin Bělohradský, CSc. *Chair*Mgr. Jakub Waldmann
RNDr. Michal Ryšavý *Audition Commission Members*

Members of the association bodies do not receive any reward for their work and all their activities are voluntary.

EMPLOYEES IN 2013

As of December 31st, Cesta domů had 39 employees (average recalculated: 26.1 full-time jobs, 31.6 including agreements).

In 2013, Cesta domů was under the leadership of the following people:

Marek Uhlíř
General Director
Irena Závadová
Senior Consultant
Martina Pojarová
Service Manager since the 1st of July 2013
Kateřina Hřebcová
Service Manager until the 31st of January 2013
Tomáš Matocha
Finance Director
Vojtěch Kozlík
PR and Fundraising Manager
Tereza Štursová
Fundraising Manager until the 7th of August 2013

Employees of Cesta domů in 2013:

Adam Houska, Adam Špinka, Alena Štěpánová, Alice Bílková, Alžběta Těšitelová, Andrea Matoušková, Anna Krutská, Antonín Krutský, Barbora Slavíčková, Dagmar Hilarová, Daniel Ryšavý, Dominika Adamcová, František Řezáč, Iva Kolářová, Ivana Pičmanová, Jan Kořenek, Jan Odehnal, Jan Vrátný, Jana Janžurová, Jana Valjentová, Jindřich Polívka, Jindřiška Prokopová, Jiří Černý, Jiřina Cejnarová, Juliána Bindásová, Karolína Pochmanová, Katarína Vlčková, Kateřina Menčíková, Kateřina Pavla Pospíšilová, Kristína Faklová, Ladislav Nohýnek, Leonardo Ragusa, Libor Vaněk, Libuše Proboštová, Lucie Vorlová, Ludmila Nohýnková, Magdalena Pehalová, Marie Kazmarová, Markéta Čábelová, Martina Dvořáková, Michaela Růtová, Mikuláš Kosák, Mlada Komárková, Olga Stránská, Ondřej Krása, Otto Adamec, Pavel Klimeš, Pavel Krása, Pavel Pokorný, Pavel Šuchman, Pavla

Vopatová, Petra Lovečková, Petra Rendlová, Romana Pavlíková, Simona Biggs, Štěpánka Ryšavá, Štěpánka Škampová, Tereza Bímová, Tereza Kaucká, Tereza Špinková, Tereza Zedková, Tetyana Bilyak, Tomáš Blažke, Václav Chytil, Veronika Němcová, Zdeněk Kalvach, Zdeňka Hůlová, Zuzana Bartáčková

...and many other people of different professions who worked for us externally or voluntarily.



Opening of the exhibition of MuDr. Oldřich Pražan's pictures in the Charity shop

CO-OPERATION

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ECONOMIC PERFORMANCE IN 2013

REVENUES	
Services and goods sold	CZK 2 885 000
Works of art sold	CZK 798 000
Donations (including the public collection)	CZK 12 700 000
Subsidies	CZK 5 034 000
Other revenues	CZK 510 000
Total	CZK 21 927 000

COSTS	
Materials	CZK 2 853 000
Maintenance, gas, electricity etc.	CZK 3 400 000
Labour costs	CZK 14 401 000
Other costs	CZK 1 495 000
Total	CZK 22 149 000

Detailed final accounts documents and the audit report are on the websites of Cesta domů.

The audit reports for the year of 2013 were conducted by the company AUDIT SERVIS, spol. $s\ r.o.$

The auditor's opinion is unqualified.