

# 2012 Annual Report

'Cesta domů', a Hospice Civic Association

## INTRODUCTION

I joined *Cesta domů* in the autumn of 2012, in the twelfth year of the existence of the organization, replacing Martina Špinková as the director. It was not a step into the unknown. I had already known *Cesta domů* as a respected and self-confident NGO which stubbornly insists on simple and clear ideas: people want to spend the rest of their lives at home with the ones they love, with quality care within their reach and with dignity – and if the health care system cannot provide its citizens with these things, it is up to us to do so. Even now, being fully immersed in its life, *Cesta domů* continues to fascinate me. What are the main features that set *Cesta domů* apart from other medical institutions in the Czech Republic?

### 1. *Where Others Stop, We Begin.*

"We can't do anything for you anymore." Thus are our patients told in hospitals. They are left with this statement, which destroys their last vestiges of hope, and they ask themselves, "Should I just wait for death in pain now?" This is when our team comes in, and the patient and her family can see just how much we can do and how important we can be by alleviating pain and sometimes even enriching their lives.

### 2. *We Do Not Follow Any Dictates*

"We can't do this. The insurance company won't pay for it." We often hear such lamentations from other institutions when it comes to costly wound healing procedures, the use of expensive equipment and even the length of doctor or nurse visits. Insurance companies do not cover a single penny of our expenses and that is why we do not have to follow anything but our own desire to offer quality palliative care without making any compromises. That means a year-to-year struggle for survival, which, however, does not let us be complacent and contributes to the unique ethos of *Cesta domů*.

### 3. *Relations*

I think I am not exaggerating when I say that we, employees and volunteers of *Cesta domů*, love and appreciate each other. That is also what our patients and their families appreciate about our job – respect, sincere interest in the patient, human support, and help through the difficult journey. Adding a high level of expertise and professionalism to the personal qualities, I dare say that the team of *Cesta domů* is second to none. *Cesta domů* and its unique atmosphere are also created by the people around it: sympathizers, supporters, donors.

As for the donors: I cannot describe what gratitude we owe to the people who do not let us fall, not even in the worst financial, political and other crises. We know who *Cesta domů*, year after year, owes its existence to and we greatly appreciate it. We have done admirable work together. I wish for myself but, more importantly, for the whole *Cesta domů* that the same could be said in a year when we look back at the thirteenth year of existence of *Cesta domů*.

Marek Uhlíř

## REGISTERED OFFICE AND CONTACTS

### Hospice Civic Association Cesta Domů

Bubenská 3, 17000 Praha 7 / Phone + fax 266 712 610

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

### Home Care Hospice and Advisory Center of Cesta Domů

Boleslavská 16, Praha 3 / Phone 293 850 949 / Mobile 775 166 863 / Fax 220 876 638

#### Bank connection:

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

Donation account: 196750216/0300

Certificate proving a public collection started in November 2011: S-MHMP/1028471/2011

#### Websites of Cesta domů:

[www.cestadomu.cz](http://www.cestadomu.cz) – presentation of the association and its services

[www.umirani.cz](http://www.umirani.cz) – information, discussion and advisory portal

[www.pod-strechou.cz](http://www.pod-strechou.cz) – home with hospice care

[www.nezavirejteoci.cz](http://www.nezavirejteoci.cz) – campaign to promote palliative care

[knihovna.cestadomu.cz](http://knihovna.cestadomu.cz) – Library of *Cesta domů*

[vzpominky.nezavirejteoci.cz](http://vzpominky.nezavirejteoci.cz) – virtual memorial site

[www.facebook.com/cestadomu](http://www.facebook.com/cestadomu) – website for supporters

### HOSPICE CIVIC ASSOCIATION CESTA DOMŮ

The hospice civic association, Cesta domů, was founded in 2001. By the end of 2012, the association had 69 members. Its mission is to promote and develop palliative care in the Czech Republic. The association established and runs the Cesta domů home care hospice in Prague, which assists families that look after their dying members at home. In addition to direct client care, there are other services connected to the hospice. For instance, the association also focuses on awareness-raising, educational and publishing activities aiming to improve care for people at the end of life in the Czech Republic.

### ACTIVITIES OF CESTA DOMŮ IN 2012

#### Home Care Hospice

The Home Care Hospice now works under the leadership of Irena Zavadová. In 2012, she replaced Jana Valjentová who was preparing for her attestation. Anna Krutská is the Head Nurse. The Home Care Hospice team provides specialized *lege artis* palliative care for special case patients who hospital doctors are uncertain whether home care is even possible – these patients suffer from very complicated symptoms or require highly specialized procedures.

Our Home Care Hospice is a registered, non-governmental medical institution. We struggle to provide a highly professional service so that the terminally ill are able to spend the rest of their lives with dignity, without unnecessary pain and misery, among their beloved ones and, if possible, in a domestic environment. In 2012, the multidisciplinary team consisted of two doctors, six nurses, six emergency and volunteer doctors, a field psycho-social worker, a chaplain and dozens of volunteers.

In 2012, we provided 119 patients with professional palliative care in their domestic environment 24 hours a day, 7 days a week.

Compared to 2011, we were able to care for 7 patients more, and at any time in 2012, we were taking care of an average of 12 patients (three more than the previous year). Our team performed 3,016 home visits to our patients, which means a 20% growth compared to 2011. The average duration of one visit was 69 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 an economically active age group. The sad fact that our patients are received later than possible unfortunately still persists – last year an average patient spent the last 36 days of their lives (the average being 17 days) in our Home Care Hospice. This shows a lack of awareness of doctors in inpatient facilities about home palliative care.

The cost of one day of treatment of one patient in our care was approximately CZK 1,900. As in the past years, we were able to provide our patients with care only through the kindness of our supporters and sympathizers – the expenses of the Home Care Hospice were financed mostly through grants and donations from both individuals and legal entities. Thanks to these donors, we managed to keep the amount of CZK 200 a day as the contribution of the patients or their families.

**Our expert guarantor in 2012 was again** MUDr. Ondřej Sláma, Ph.D.; at the end of the year, Irena Závadová received her attestation in palliative medicine, and we applied for her license as a senior consultant.

### Home with Hospice Care “Pod Střechou“

On April 13<sup>th</sup> 2012, Cesta domů and the Prague 2 Municipal District opened *Domov Pod střechou* (Home Under the Roof) – the first hospice facility any of its kind in the Czech Republic. The basic principle of the project is to offer space and staff to those who cannot take care of the terminally ill in their families 24 hours a day and want them to die with dignity in a nice environment. Palliative care is provided by the Home Care Hospice, Cesta domů.

In 2012, *Domov Pod střechou* received a total of 19 patients. Except for one sole patient, all patients had families who often visited them, and a few relatives even slept in the room. There were also several interns from different parts of the country coming to *Domov Pod střechou*, several film crews filmed here, and just before Christmas, we welcomed the advisor to the Minister of Health, MUDr. Pavel Vepřek.

### Medical Equipment Rental

We provide the families of the patients of the Home Care Hospice with electric adjustable beds, various types of wheelchairs, active and passive antidecubitis mattresses, oxygen concentrators, infusion pumps, pulse oximeters, linear medicine dispensers, aspirators, inflatable tubs, electric tub hoists, toilet chairs, walkers, specialized antidecubitis aids and other minor aids. In 2012, 226 aids were rented to 73 patients of the Home Care Hospice Cesta domů.

236 aids were rented to a total of 152 clients from the public (in addition to the patients of the Home Care Hospice Cesta domů). The rental worked under the leadership of Petra Husáková.

### Professional Social Consulting

The Cesta domů advisory centre, managed by Kateřina Hřebcová, 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 center employees assist the inquirers in their new situation. They help them choose an appropriate service or facility, obtain necessary contact information and learn the basic nursing procedures needed when taking care of a seriously ill person. The center employees also explain the principles of home care hospice services and mediate the first contact before starting hospice care.

In 2012, the center employed 6 consultants who completed 1,756 interviews with a total duration of 476 hours. A social worker visited clients 456 times. A psychotherapist undertook 29 consultations with clients. Our online consulting center provided its services to people from all around the Czech Republic who could consult a doctor, a social worker or a psychotherapist. The published answers are, however, not only read by the ones who asked the question. In 2012, the advisory center was again the most visited site of Umíraní.cz. With up to 1,500 visits a day, its role in the Czech Republic is irreplaceable. We believe that our consulting services as well as the portal contribute to the spreading of knowledge among the interested public of the possible ways of helping dying people and the bereaved. Although the Ministry of Labour and the Ministry of Social Affairs classified our advisory center as a regional service with competencies only in Prague, we continue to provide our advisory services to people from all around the Czech Republic – people from outside Prague made up a third of our clients.

### Cesta domů Websites

Vojtěch Kozlík is responsible for all Cesta domů's websites. In 2012, the websites of Cesta domů played again

an important role in communication with our clients, supporters and donors. Having been visited by a total of 256,047 people in 2012, the portal Umírání.cz got the most attention. This website continues to be the main source of information for people at the end of life and for their carers. The advisory center mentioned above is a part of this website. Umírání.cz is regularly updated with new articles and also offers a list of educational possibilities in palliative care. In connection with the campaign, *Nebojme se zbytečně* (Let Us Not Worry Needlessly), web traffic reached up to 2,000 visits a day with tests and advisory center being the most popular pages. We are also pleased that the campaign has inspired other independent persons to other activities, spontaneously following the campaign.

The Cestadomů.cz websites serve to promote the services provided by Cesta domů and other activities of the organization. In 2012, these websites were visited by an average of 276 persons a day.

A great deal of attention was also paid to the *Vzpomínky.nezavírejteočiči.cz* websites (*Memories.dontcloseyoureyes.cz*) where the bereaved can share memories of their beloved ones through virtual memorials – last year, their number reached 625. The community of people our websites help at the time of bereavement continues to increase. In 2012, we intensified our activities on our Facebook page, through which we manage to reach the target group between 25 and 35 years of age.

### Respite Services

Our Respite Services, managed by Karolína Pochmanová, were joined by several new assistants and became a popular and valued service of our organization. In 2012, assistants visited 26 families during 513 visits, which adds up to 5,128 hours of respite services. The most usual duties our respite services assistants performed were helping the clients to dress, eat, wash, etc. Their presence often supplemented the absence of close family members. The clients therefore did not need to go to the hospital and could stay at home among their beloved ones.

### Podvečer (Late Afternoon) Club

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. In 2012, the club met earlier in the afternoon, operating under the new leadership of a field social worker who had already met some of the clients in the Home Care Hospice. These changes have proved their worth and interest in the meeting increased. The ergo-therapeutic workshops continue to be a favorite activity as well as the meeting of our bereaved, our employees and our volunteers in the Sue Ryder Home, the second Thursday after Halloween.

### Library

The library run by Cesta domů is the only public library in the Czech Republic specialized in palliative care. It is a unique collection of books dealing with the care for dying patients and other related issues including numerous international publications, elsewhere unobtainable. In 2010 the library continued to help professional and lay circles and students of various courses to find their bearings in palliative issues. The library offers and uses an interlibrary lending system, thus serving readers all over the country (we lent 105 titles to other libraries). 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. The library is run by Ludmila Nohýnková under whose care it is slowly increasing in volume. In 2012, 195 books, 118 audio books and 14 audiovisual media or electronic resources were acquired for a total of over CZK 70,000. We thankfully state that 192 were obtained as gifts, the remaining 135 books or other information carriers were bought.

The library contains over 3,200 titles. A total of 1,038 readers visited our library and borrowed 4,078 books. The online catalog was visited 1,052 times and a total of 36,555 enquiries for a particular publication were raised.

### Publishing Activities

In 2012, thanks to the support of the Ministry of Health, we printed new editions of several time-proven information leaflets and detailed brochures in a new graphic design.

In the autumn of 2012, we published a catalog accompanying a charity auction with reproductions of works of art offered at the auction.

Before Christmas, we released a unique set of stationary printed with original graphics by Martina Špinková. The set contained gift items such as notebooks, greeting cards, letter papers, gift packaging and bookmarks. The proceeds from the sale went to support the Home Care Hospice.

### Educational Activities

We presented lectures for both the general public (schools, interest groups, debates, presentations) and the professional public (health schools, medical faculties, clinical departments). We spent dozens of hours training the staff of the Home with Hospice Care Pod Střechou. Our medical staff also got actively involved in organizational and lecturing work in ELNEC (End-of-Life Nursing Education Consortium).

### For the Public

During the first third of the year 2012 Cesta domů, with the support of many partners, organized a campaign called, *Nebojme se zbytečně* (Let Us Not Worry Needlessly). Its aim was to present human mortality as a basis for providing good end-of-life care and for improving this care in the Czech Republic. During two consecutive months, February and March, Czech Television aired the spot, *Let Us Not Worry Needlessly*. The spot was shown on all channels at all broadcast times. Other media contributed through interviews on the radio, on TV and in newspapers. Posters accompanying the spot were placed in Prague's trams and metro, and the spot was also modified for the Metrovision system in metro stations. An issue of the Czech daily, *Lidové noviny*, before Eastertime contained a leaflet from the campaign. For the ninth time, Cesta domů joined the celebrations of the World Hospice Day that were held all over the world on October 13<sup>th</sup>. The bands *Bra-Agas* and *Bachtale Apsa* with Mário Bihár played a concert in La Fabrika.

### Volunteers

In 2012, the work of the volunteers in Cesta domů was supervised by Tereza Bímová and Olga Cordiner. As in past years, volunteers helped with administrative work, with organising various events, and in the bereavement club. They also helped in clients' families and with the transport of aids from the rental.

Also, the volunteers worked 426 hours in the library and in the office. The amount of time volunteers spent taking direct care of our patients in their homes or in our Home with Hospice Care increased significantly from 265 hours in 2011 to 1352 hours in 2012. Moreover, volunteers worked 400 hours during cultural, educational and benefit events and 261 hours transporting aids to and from our clients (transportation of electric adjustable beds was among the most common duties). Volunteers as well worked for 352 hours in the charity shop, *Krámek na cestě domů*. On the whole, they spent 2791 hours doing 864 different activities for Cesta domů in their free time and for free.

In April 2012, 16 volunteers completed their preparatory course. In October the X. cycle of volunteer training was launched with a total number of 16 applicants enrolled, 14 of whom completed the training successfully in April 2013.

### Support and Inspiration

In 2012 the common denominator was the organization of various events by third parties, mostly independently of Cesta domů. Some the most enjoyable were the traditional charity concert in the church of St. Markéta in Břevnov, Prague, the massage day of the *Zdraví studio*, the jumble sale called *Dobrobazar* in Čestlice, Prague, a charity concert in the Clementinum in Prague organized by our volunteer Jana and, last but not least, a concert of bands made up of our employees' children called, *Mladí hrají Cestě domů* (The Young Play for Cesta Domů). There were also several birthday celebrations in which guests were asked to contribute to a moneybox for Cesta domů instead of buying a traditional birthday present.

In the course of the year, members of the reading group, *Veselé poutnice* (Merry Pilgrims), prepared the publication of a unique audio book called, *Spolek přátel krásné literatury a bramborových koláčů* (The

Society of Friends of Belles-Lettres and Potato Cakes), which was published in the autumn along with an accompanying family calendar, which met with a great success. Another interesting event was the second annual art auction organized by generous artists and willing benefactors—the outcome being a large support for our activities.

We would like to thank everyone for all the support and encouragement that such help brings.

### Perspectives

By the end of 2012, preparations for adaptations and moving into new spaces were in full swing. The spaces in Boleslavská Street were acquired thanks to the support of the Prague 3 Municipal District. In 2013, our direct care teams, administration facilities and the library will operate in larger spaces under one roof after a long time. We will continue to strive for decent conditions not only for the dying and their families but also for our employees and volunteers. We will also start preparations for the transformation of our civic association into a registered institution in accordance with the new Civil Code in 2013.

Given the persistent uncertainty in terms of funding of mobile palliative care, we continue to pay a great deal of attention not only to effective fundraising, but also to promoting system changes and the concept of good dying at home. We believe it is necessary to create a network of loosely cooperating entities with common goals – also internationally – in order to achieve our ambitions with an overall social perspective as far as the issues of death and dying are concerned. Also important are the efforts to work systematically in the field of training of helping professions in the Czech Republic. We will endeavor to support education for nurses (the international project ELNEC), to take a more active part in undergraduate and postgraduate training of doctors, and to encourage the exchange of experience on the management level in institutions working with people dying in a domestic environment through exchange visits and work in a forum for mobile specialized palliative care. We will continue to work closely with the Czech Society of Palliative Medicine and the Czech Medical Association of J. E. Purkyně.

### ASSOCIATION BODIES

#### Association Board in 2012:

RNDr. Josef Basík

*Association Chair until August 2012*

Academic painter Martina Špinková

*Association Chair since August 2012*

Mgr. Václava Bratinková

*Association Vice Chair*

Prof. RNDr. Milan Kodíček, CSc.

*Association Vice Chair*

Doc. MUDr. Štěpán Špinka, PhD.

*Association Vice Chair*

Ing. Richard Kaucký

Mgr. Ondřej Krása *since October 1, 2012*

Mons. ThLic. Tomáš Holub, ThD.

JUDr. Rostislav Silný

*Association Board Members*

#### Association Audit Commission:

Ing. Martin Bělohradský, CSc.

*Chair*

Mgr. Jakub Waldmann

RNDr. Michal Ryšavý

*Audit Commission Members*

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

## EMPLOYEES IN 2012

As of December 31, Cesta domů had 29 employees (average recalculated: **25.5 full-time jobs, 30.2 including agreements**). In 2012, the following people worked for Cesta domů:

Martina Špínková

*General Director until August 2012*

Marek Uhlíř

*General Director since September 2012*

Jana Valjentová

*Home Care Hospice General Manager until January 2012*

Irena Závadová

*Home Care Hospice General Manager since February 2012*

Bc. Kateřina Hřebcová

*Services Manager*

Tomáš Matocha

*Finance Director*

Vojtěch Kozlík

*PR and Fundraising Manager*

Ondřej Krása

*Fundraising Manager until March 2012*

Adamec Otto, Bílková Andrea, Bímová Tereza, Cejnarová Jiřina, Conková Michaela, Cordiner Olga, Čábelová Markéta, Dvořáková Martina, Hilarová Dagmar, Houska Adam, Chytil Václav, Janžurová Jana, Kalvach Zdeněk, Klimeš Pavel, Kolářová Iva, Kosák Mikuláš, Krutská Anna, Krutský Antonín, Kudrna Lukáš, Lovečková Petra, Matoušková Andrea, Menčíková Kateřina, Nohýnek Ladislav, Nohýnková Ludmila, Pavlíková Romana, Pehalová Magdalena, Peňasová Ilona, Pičmanová Ivana, Pochmanová Karolína, Pokorný Pavel, Polívka Jindřich, Pospíšilová Kateřina Pavla, Proboštová Libuše, Prokopová Jindřiška, Ragusa Leonardo, Rendlová Petra, Ryšavá Štěpánka, Slavičková Barbora, Šimková Hana, Škampová Štěpánka, Špinka Adam, Špínková Tereza, Špínková Marie, Štěpánová Alena, Štursová Tereza, Tesárek Radim, Těšitelová Alžběta, Vopatová Pavla, Vorlová Lucie, Zedková Tereza

...and many more people from different professions who worked for us externally or voluntarily.

## CO-OPERATION

### Institutions

Capital City of Prague, Ministry of Labour and Social Affairs of the Czech Republic, Ministry of Health of the Czech Republic, Ministry of Culture of the Czech Republic, Municipal Districts of Prague 1, 2, 3, 4, 6, 8, 9, 10, 12 and 13, National Medical Library, Municipal Library of Prague

### Foundations and Non-Profit Organizations

Českobratrská církev evangelická, Divadelní soubor Ty-já-tr, Divadlo v Dlouhé, Diplomatic Spouses Association, Druhý sbor ČCE v Praze 3 – Žižkově, Fabián Brdy o. s., Fórum dárců – DMS, Knihovna a tiskárna pro nevidomé, Laděk o. s., Liga proti rakovině, Nadace AGROFERT HOLDING, Nadace Charty 77 – Konto Bariéry, Nadace Dětský mozek, Nadace Vodafone ČR, Nadační fond AVAST, Národní divadlo, Turistický Akademický klub Praha, Výbor dobré vůle – Nadace Olgy Havlové, Římskokatolická farnost Čestlice, Římskokatolická farnost Michle

### Corporate Partners

ABC MAGNET s. r. o., ACI – auto components s. r. o., Aedes s. r. o., Adastra s. r. o., Agentura Sarah s. r. o., Airport Outlet s. r. o., Akronym s. r. o., ALFIX ČR s. r. o., ALS s. r. o., Alza.cz, a. s., Amgen s. r. o., Anect, a. s., Auto Components International s. r. o., Centrum dohody s. r. o., Citibank Europe plc, organizační složka,

Coca-Cola HBC Česká republika, s. r. o., Coffeesource s. r. o., ComAp spol. s. r. o., Česká televize, Dignita s. r. o., DMA Praha s. r. o., ECONOMIA, a. s., ENERGY 21, a. s., EP-SC s. r. o., Eppendorf Czech & Slovakia s. r. o., Explore Productions s.r.o, FBE Praha s. r. o., GE Money Bank, a. s., Gold Pralines s. r. o., GT ateliér GEODÉZIE, Hypnosis s. r. o., Immunia s. r. o., JAVLIN, a. s., JCH ART AGENCY PRAGUE s. r. o., JK Machinery s. r. o., Jp Soft s. r. o., Karmelitánské nakladatelství, KIM Group s. r. o., Knihkupectví Kosmas, K. E. Macana, Kolektory Praha, a. s., KP Troja, s. r. o., La Fabrika, Lázně Bělohrad a. s., LEKIN, s. r. o., MAXIMA REALITY s. r. o., MEDESA s. r. o., Megabooks cz s. r. o., Merten Dental, Nakladatelství Grada Publishing, Nakladatelství GEUM, Nakladatelství PORTÁL s. r. o., Nalia Finance s. r. o., Neubauer a syn s. r. o., NET4GAS s. r. o., NEWTON Media, a. s., Persona Grata v. o. s., Petr Lacina – Masážní studio ZDRAVÍ, Pivovar Herold Březnice a. s., Pokladnice vín, Potten & Pannen – Staněk group s. r. o., První agenturní, a. s., Radioservis a. s., Rámy pasparty s. r. o., RES-UH s. r. o., Software602, a. s., Společná advokátní kancelář Korbař, Pokorný a spol., STEM/MARK a. s., Střížkovská s. r. o., Studio P.H.A. s. r. o., Sugar cube s. r. o., Syxt 4 s. r. o., Šach mat s. r. o., The Prague Concert Co., s. r. o., Tiskárna Flora s. r. o., Transfinance, a. s., a, UniCredit Bank Czech Republic, a.s, Ústav experimentální medicíny, ÚVT, s. r. o., VIZUS. CZ s. r. o., Yves Rocher s. r. o., Wealth Management Services a. s.

## ECONOMIC PERFORMANCE IN 2012

REVENUES	
Services and goods sold	CZK 2 513 000
Auction	CZK 622 000
Donations	CZK 10 481 000
Subsidies	CZK 4 770 000
Foreign sources	CZK 197 000
Other revenues	CZK 560 000
<b>Total</b>	<b>CZK 19 143 000</b>

COSTS	
Materials	CZK 1 782 000
Maintenance, gas, electricity, etc.	CZK 1 918 000
Labour costs	CZK 13 238 000
Other costs	CZK 1 053 000
<b>Total</b>	<b>CZK 17 991 000</b>

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

The audit reports for the year of 2012 were conducted by the company AUDIT SERVIS, spol. s r.o.

The auditor's opinion is unqualified.