

דיסמן, עם בתו החד.  
"לא יכול לדאוג את  
החיים שלי בלעדיה"

Zysman with his daughter Hadar.  
"I can't imagine my life without  
her"

# I Dream of Calling Daddy

**When she was two years and seven months old, Hadar – daughter of attorney and former professional basketball player Shmuel Zysman – was diagnosed with Rett Syndrome. Zysman refuses to give in to the disease that has made his daughter completely dependent upon those around her. Now, following scientists' successful treatment of the disease in a lab rat, he has decided to come forward in order to raise funds for innovative genetic research.**

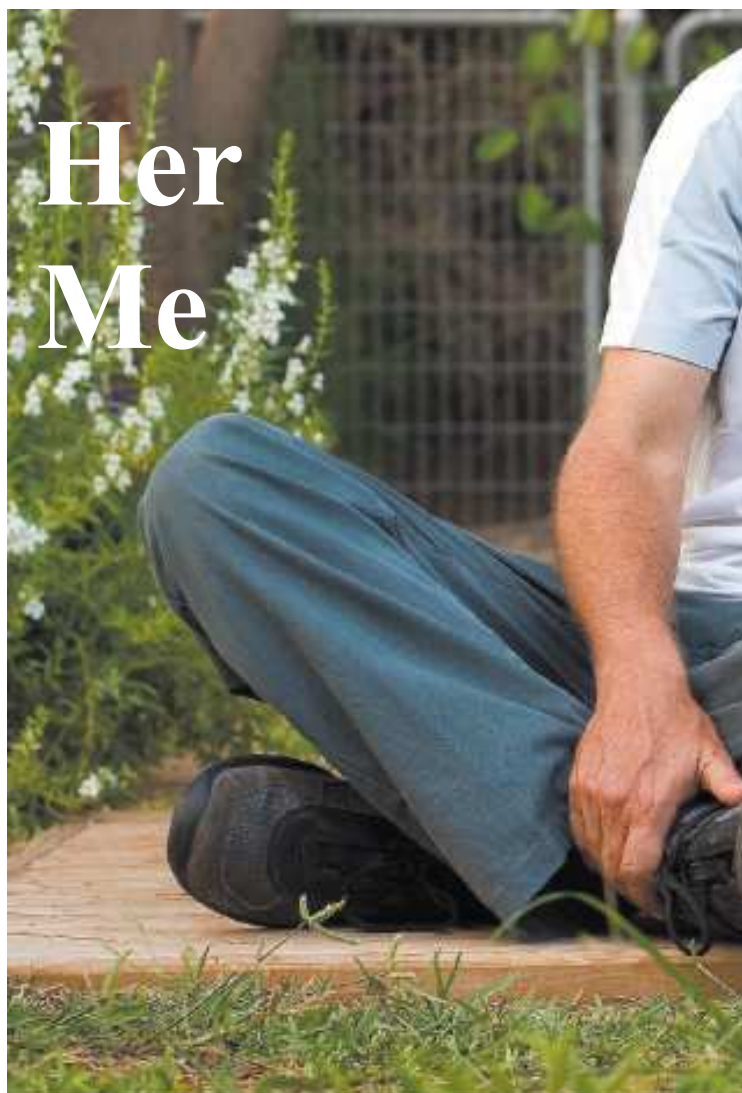
“Every time she moves her mouth, I beg her, ‘Hadari, please just say Daddy’, and she always laughs and remains silent. My greatest dream is for her to call me Daddy” says attorney Shmulik Zysman, weighing his words carefully, as if trying to control the externalization of his pain.

It is heart wrenching to see the sweet, silent girl with the unfocused look in her eyes who constantly wrings her hands as if perpetually washing them. She can barely walk on her own and must be accompanied every moment of her life. Hadar Zysman is afflicted with Rett Syndrome, but her father, a successful attorney and former professional basketball player, refuses to give up. This is clearly the most important game of his life and he knows that he must defeat the cursed disease, which only attacks baby

girls who were born healthy. When they are approximately 18 months old they begin to regress, eventually becoming unable to move their bodies or speak. Thus, they are called “Angels of Silence”. The Zysman family has been coping with the disease for nearly a decade.

Few people take part in this part of Zysman’s life. “I have never hidden Hadar. She accompanies us to every function and I want to make it clear that she is a member of our family and that I have her back. But because I’m known in Israel, thanks to my past as a basketball player, I was concerned that if our story were made public, people would think I sought pity and that’s the last thing I want. Hadar brings joy to our lives, despite the many difficulties”, he says.

Lilit and Shmulik Zysman raised three children in their well-kept home near Tel Aviv: Lior (12), Hila (9) and Shahar (4). They decided to add another child to their existing brood of two boys and one girl, hoping for a daughter, to balance things at two each. They were ecstatic when they found out during pregnancy that indeed they were to have a second daughter. Hadar was born on December 9, 1996. There was nothing unusual about the birth. Her father was present and just as excited as if she were his firstborn. “Hadar was an exceptionally charming baby and we were all excited to have her join our family. There was nothing to make us think that there was anything wrong with her. She developed and grew like any other child. Only afterward, when playing things



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back in my mind, did I recall saying goodbye to Hadar before leaving for work and asking her to wave goodbye, which she didn't do. I left the house thinking, 'She doesn't know her father yet. But at some point she'll know and love me and then she'll wave goodbye wholeheartedly'.

"I didn't take it too hard. I knew she was still young. But that scene is etched into my mind. Later, when Hadar was eight months old, my wife went out one evening and asked me to put her to bed at 9 o'clock. I considered how best to accomplish the task. I thought that she would probably want to stay up and play and refuse to go to sleep. Nine o'clock came. I put her into her bed and she fussed a bit, but then she crumpled like a sack of potatoes and fell asleep. I was pleased to have been so successful. Again, in hindsight, a few months later, I told myself that something was not quite right".

## We Were Concerned

"At the age of about one year, we realized that her muscle tone was problematic. Due to my background as an athlete and based on some paternal instinct, I began to stimulate and move her limbs much more so than with a usual child. We consulted various doctors who all told us the same thing: 'She is simply developing slowly. She'll progress at her own pace, there's nothing to worry about'. Yet, as experienced parents who had already raised three children, we were concerned. We consulted doctors in Israel and overseas, but none of them provided answers that could calm our feeling that something was wrong with our child.

"One doctor off handedly mentioned Rett Syndrome, but said that we shouldn't consider that possibility because it was too awful. From that moment on, I couldn't get the thought of Rett out of my mind. I went onto the internet and read an appalling description of a disease in which healthy baby girls suddenly deteriorate, lose all their capabilities and live to age 15 at most.

"I tried not to panic, because in the meantime Hadar was developing and had begun to crawl, although her progress was



Lilit and Shmulik Zysman already had three children: Lior (12), Hila (9) and Shahar (4). They decided to add another child to their family and hoped for a daughter, to balance things out. Hadar was born in 1996 and they were ecstatic

"Only one doctor talked to us about Rett Syndrome. I went onto the internet and read an appalling description of healthy baby girls who deteriorate suddenly, lose all their capabilities and live only to age 15"

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slow. When she was two years and seven months old, a pediatric conference was held, attended by doctors from all over the country. They asked us to bring Hadar so that a group of doctors could try to diagnose her together. The verdict was decided in a matter of minutes: Hadar had Rett Syndrome”.

## What do you do when a bomb like that is dropped on you?

“I was in shock. When we left, Lilit, Hadar and I went to a nearby café. After ten minutes of tears, it was clear to me that some good had to come out of this. I told my wife that this child would provide some of the happiest moments of our lives. With that in mind, we began taking care of her and never gave up. Hadar has never spoken, played on her own or held a fork and fed herself. Her gait is unsteady and heavy. But I decided that I was not going to let her deteriorate, that she would indeed progress. That changed my life and my long standing practices. I had previously worked long hours, but from the moment her condition was defined by name I have made sure to be home on time. I put her to bed and never miss an opportunity to see her, play with her and mainly, to hug her.

“I make a point of returning home for the weekend if I’m travelling and I have thrown myself completely into the fight against Rett Syndrome and my child’s loss of her abilities. When Lilit and I were a young couple, I was engrossed in building my career as a basketball player and an attorney, which used up a lot of energy. My wife said to me on many occasions, ‘Look at how other couples live. The husband comes home at 5 p.m. and spends time with his children. You don’t have time for that’. I replied, ‘Believe me, when you need me, I’ll be there’. And that is what happened. I try to spend as much time as possible with Hadar because I know how important it is for her and for me”.

## Do you ever question why this happened specifically to you?

“Never. This disease is not genetic and it could in fact affect anyone. From the moment my daughter’s condition was diagnosed, I haven’t shared this with anyone. Even my family and my wife’s

family were not really involved. The two of us took it all upon ourselves. We said that this was our mission and that we’d be up to it. We updated our families and my business partners occasionally, without going into too much detail”.

## Why?

“I don’t talk about it very much for fear that people might think I need help. It must be something in my personality. Hadar is my daughter, even if she can’t walk alone or speak. She means the world to me. Despite all the difficulties, and there are many, we are taking a wonderful journey with her. On more than one occasion I’ve looked at the situation from a seemingly backward angle and said to myself that the world is truly a strange place. As a basketball player, I was able to use my body in unusual and unique ways, despite the fact that I’m not really built well for basketball. And now, I must teach my daughter to use her body and physically support her so that she doesn’t crash to the floor. What a difference between what I was, between what I’d like to teach her, and what she actually is. I should have been teaching her how to pass the ball behind her back or to spin the ball on her finger, as I did with my three healthy children. But Hadar’s hands cling together as if an electrical current pulls them toward each other”.

## How do you gather the strength to deal with this?

“At first, we were completely hysterical. All we knew was that a terrible clock was ticking against us and that our daughter’s life expectancy was 15 years. It is a horrible thing to even consider. We went all over the world trying to find a way to save our daughter and no one could help us, as very little was known at that time.

“I told myself that we would do everything possible. We’d concoct medication, give injections, participate in trials. Utilize anything that had even a remote chance of changing her condition. Today I won’t even give her an aspirin because I’m concerned about what effect it might have on her. One time when we went to see the Head of Pediatrics at a major hospital, he looked into Hadar’s eyes and said, ‘She’s a very intelligent girl’. I remember that statement and it gave me great strength. The doctor perceived something about her very essence. Her eyes spoke back then and continue to do so. We work with her


through those eyes. When Hadar was diagnosed with Rett Syndrome she had just begun the transition from crawling to standing. We could see how she held onto the table and pulled herself up from the floor. But at the same time, the doctors told us that she would not continue to progress, but rather would regress”.

## How does one react to such news?

“I couldn’t accept it, I saw how determined she was. She grabbed on to the table and began walking around it. Although she would fall after only a number of seconds, I was not alarmed and I didn’t let her give up. She kept standing and falling and it was okay. We replaced all the floors in the house with parquet. We made the house level so that she wouldn’t have to cope with stairs and slopes. We created the safest possible environment for her. I realized that no one could give us advice and that I had no choice but to trust my own instincts.

“There was one professor at Johns Hopkins Hospital in the U.S. who explained to me that girls with Rett Syndrome have no memory because they are unable to mimic. Intuitively, I felt that she was wrong. Every Saturday I took Hadar to the beach and tried to stand her up on the soft sand. There are always a million people there on the weekend and we always sat in the same place. After going a number of times, Hadar remembered the precise way we walked from our chairs to the water. Every Saturday she took the exact same route. I understood that the honorable professor had been completely mistaken and that Hadar does have a memory. No one had simply ever bothered to test how memory is manifested in Rett sufferers. At that moment, I experienced my first a glimmer of hope”.

## A Computer Operated with the Eyes

Hope is what fuels the 51-year old Zysman, it drives him and fills him with great energy for anything related to his ill daughter. He invests vast amounts of energy and huge sums of money toward promoting Rett Syndrome research. As an attorney in the global hi-tech industry, Zysman has recently been busy searching for a computer that Hadar will be able to operate with her eyes. “I sit beside her and have the feeling that she is saying, ‘Relax, Daddy. Everything is okay’. Rett is a mystery, but one thing is 

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extremely clear: within that body exists is a complete soul that must be communicated with in unfamiliar and unusual ways. I do everything possible to communicate with my daughter”, he says as he strokes her face. But she is in her own world. Zysman searches her eyes, which are usually cast downward toward the floor. There is no greater joy than when he makes contact with her pupils. Sometimes she makes unintelligible guttural sounds and prefers to look at the television, especially when the image is fast forwarded. This preference poses a puzzle for Zysman. He assumes that his daughter’s perception is so rapid that the regular pace of television broadcasts makes her impatient. Go figure.

He likens her manner of functioning to an orchestra without a conductor. “She perceives everything and has within her an endless number of instruments, but is unable to externalize things in an organized way”. His wife defines her daughter’s condition as an body confined within a body. They both realize that the easiest solution would be to sit Hadar in a wheelchair or carriage rather than fight for each step, but they are determined to pose challenges for her and not to give in to her limitations.

Hadar must go up a number of steps in order to reach her room on the second floor of their home. Thus, an adult must support her, and she is no longer a light weight child. Zysman has recently begun to consider installing an elevator to make it easier on those who accompany his daughter.

Zysman made it clear to his family that they must all accommodate themselves to Hadar and she is never left out of family vacations. They are planning to celebrate her Bat Mitzvah in December with a trip to Thailand, including all the attractions. Zysman is certain that Hadar will show everyone her capability to experience joy.

“The satisfaction I feel in being able to teach her to stand and ski doesn’t compare to scoring the winning basket in any game. Not even to win a gold medal. It is so much more than that. This is real life”, he says as he switches on his laptop computer and, like any proud father, shows us pictures of his daughter skiing with his help in the French Alps.

He invested great effort in finding an instructor for her, a young Druze man from the Israeli village of Majdal Shams who works in La Plagne, France, who connected with her at once. Zysman speaks of it excitedly. “As soon as Hadar met him he said that she was his lucky charm and he gave her his all”, he recounts. The family has returned every year since and Hadar skis alongside her instructor and her father.



Zysman (Maccabi Tel Aviv) with the European championship cup.

“After the diagnosis I was in shock. After ten minutes of tears, it was clear to me that some good had to come out of this. I told my wife that this child would provide some of the happiest moments of our lives”

“I asked Nochi Dankner, who has been a close friend since our days in school, to host a fundraising event in his garden. Nochi surprised me when he simply pulled out his check book and wrote out a check for 1 million NIS (nearly \$300,000) from his personal account. I was stunned”

**What do you enjoy doing with her the most?**

“Hugging her and breathing in her scent. She is my blood pressure medicine. When I hold her, my pressure goes right down to 120/80, because she’s extremely important to me. The bond we have is real, a pure link with no intervening interests. Despite the fact that she has never spoken a word, she knows I’m there for her and she grants me her love in return. I know she relies on me completely and I don’t intend to disappoint her”.

**“Yes” and “No” Answers**

For years girls afflicted with Rett Syndrome were considered mentally retarded. Some spent their lives in psychiatric hospitals and others were sent to homes for the mentally retarded. Today, the life expectancy of Rett sufferers is not limited and some patients are in their 30’s and 40’s. Zysman always insisted on treating his daughter like a regular child. When he was unable to find existing literature regarding the intelligence level of girls with Rett Syndrome and ways to teach them, he decided to discover for himself what would work for his daughter.

He asked her a number of simple questions, the answers to which were “yes” and “no”. If she tapped his right hand, this signaled a “yes” while a tap on his left hand signaled “no”. He eventually enhanced the system by writing “yes” and “no” on pieces of paper, to which she would point. Today she constantly carries a small purse. When opened, the words “yes” and “no” are written on either side. This is how her classmates communicate with her. But Zysman was not satisfied with simple questions and progressed even further. He asks her ‘Who is currently the Prime Minister?’ and places two options before her: Ehud Olmert or Ehud Barak. Hadar points to Olmert and her father beams with joy.

He constantly seeks proof that his daughter absorbs information in her own special way, although she is unable to verbalize that information. As the Chairman of the Competitive Sports Administration he was responsible for preparations for the Beijing Olympics. During one of his recent trips to China he told Hadar over the phone where he was, how hot it was there, what the Olympics and medals are, who the competitors are, etc.

After the conversation, he asked his son to ask Hadar questions



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having to do with that conversation. When he got off the plane after landing back in Israel his son sent him a text message that read: '5 minutes, 10 questions, 10 correct answers'. The stunned Zysman racked up another victory for his intuitions about his daughter.

During the past ten years Hadar has been swimming with private instructors, riding horses and treated by a language clinician. Alberto Aylon, who has been Zysman's fitness coach since his professional basketball days, and Mark Or, his personal trainer, also work with Hadar. They come to the house a number of times each week to battle her stiff body.

Zysman takes her walking on the beach and stair climbing in the local amphitheater to prevent her from walking on her toes, as is characteristic of Rett girls. She currently attends the Anthroposophical School as part of a special class. For three hours each day she is integrated into a regular class, with a special aide in attendance at all times.



In their garden at home. "The study that claims the disease is reversible is a turning point for me"

"We replaced all the floors in the house with parquet. We made the house level so that it would have no stairs and slopes. We created the safest possible environment for her. I realized that I had no choice but to trust my own instincts"

Actress Julia Roberts got involved in raising money for Rett girls, after getting to know a girl afflicted with the disease for whom her sister used to babysit. Roberts fell in love with the little girl and has been volunteering for the cause ever since



**How much does it cost a family to care for a Rett child, who is 100% dependent?**

“Ridiculous sums, reaching six figures each year. I understand that not all families are able to bear such a financial burden and I help them as well. I have established The Rett Syndrome Center which deals in identifying and providing professional aid to ill girls. I finance research and conferences on the subject as well as fun activities for the girls and their families. A year before Hadar was diagnosed with Rett Syndrome I founded a non-profit organization called Lev Ohev (loving heart) which provides care for special needs children. I didn’t realize then how close I would be to the subject of disabled children. I’ve wondered many times if Hadar’s illness was a self fulfilling prophecy. The thought tortured me. The issue came full circle when members of the organization came to me and asked that we help Rett girls as well. Lev Ohev has proved meaningful for the families ever since.”

**Is Hadar treated differently than your other children, given her condition?**

“I have wonderful children and thankfully they are also talented, so they will be able to take care of themselves. Hadar is definitely different.

When I come back from abroad she is my top priority. Besides our office in Israel, we have opened offices in the U.S. and China.



**Roberts. She fell in love**

I have hired local attorneys for those offices so that I don’t have to be there. I don’t want to travel and be away from Hadar. Missing her is different, somewhat out of control. On more than one occasion I’ve gone straight from the airport to one of her lessons in order to be with her”.

**How much does the subject of death occupy your mind?**

“My dream is to see Hadar healthy, but I also imagine difficult scenarios. For example, Rett sufferers stop breathing a number of times during the day, and I nearly have a heart attack each time it happens. I cannot picture my life without her, either emotionally or intellectually. I worry about who will care for her as lovingly and

understandingly as we do after we die and I have no answer”.

**Discovering the Responsible Gene**

As fate would have it, three months after Hadar Zysman was diagnosed as a Rett child, at the age of two years and seven months, the gene responsible for the syndrome was discovered by neurologists Huda Zoghbi, a Lebanese living in the U.S., and Ruth Amir from Israel. This achievement came after research of the syndrome had been stalled for 20 years. Beyond the immense hopes raised by the discovery of the gene among the families of the ill girls, the discovery was deemed revolutionary in that it proved that Rett is not a generative disease.

Zysman did not wait for someone else to do the work for him. He immediately began donating money toward research and recruiting new researchers. Today, Rett Syndrome is one of the most studied diseases in the world, thanks to the widespread assumption that the responsible gene is also related to some cases of autism, Alzheimer’s, schizophrenia and cancer. Actress Julia Roberts got involved in raising money for Rett girls, after getting to know a girl afflicted with the disease for whom her sister used to babysit, who has since passed away. Roberts fell in love with the little girl and has been volunteering for the cause ever since.

Approximately one year ago a significant scientific breakthrough occurred within Rett Syndrome research, when it was proven that it was possible to genetically repair a rat with Rett syndrome and cure it. The possibility that Rett Syndrome may be reversible has excited researchers, who are currently working on four major studies of the subject, in the U.S., Scotland and Israel. In order to keep this momentum going, some \$5 million are required. Despite his successful law practice, Zysman is unable to fund this sum out of his own pocket and he hopes to raise the money from others. In order to do so, he decided to allow a glimpse beyond his wall of privacy.

“On one hand, revealing our story is a big step for me. On the other hand, I felt that the research claiming that Rett is reversible warrants a public appeal. Raising funds for studies that could make Rett Syndrome a thing of the past is so important and meaningful that I am willing to pay that price. It’s my small contribution to the cause”.

**To what degree can you count on the charity of others?**

“Before I began to reveal my story I discussed it with businessman Nochi Dankner, who has been a close friend since our days in school. We also keep in touch with his wife, Orly, who is a childhood friend of mine. I consulted him as someone who is well acquainted with the business milieu and whose opinion I trust. Nochi has become familiar with Rett Syndrome through us, during the ten years we have been dealing with the disease. I thought to host an event for his friends at his house in order to raise the money needed for the research. Nochi surprised me when he simply pulled out his check book and wrote out a check for 1 million NIS (nearly \$300,000) from his personal account. Not from his company, but from his personal funds. He said, ‘Shmulik, you need to come forward with your story and I’m going to help you raise the money’.



**Dankner. "First and foremost a friend"**

I was stunned and touched by the gesture. I didn’t expect it and certainly never requested it. But I know what Nochi was thinking. He is a friend first and foremost and wants to set a personal example as he plans to personally approach each of his friends to request donations for Rett research.

“That proved to me that there are good people out there and that one should not keep everything inside. Just as I’m always happy to help various organizations that approach me, others are glad to contribute toward an issue that I experience every day with Hadar”•

[anatme@yedioth.co.il](mailto:anatme@yedioth.co.il)

**To place donations please contact:**  
[www.rett.org.il](http://www.rett.org.il)

## Frequency: One in 9,000 Girls

“Rett Syndrome is a genetic neuro-developmental disease that appears mainly in girls (although also occasionally in boys). The syndrome is considered to be the second most frequent genetically based cause of mental retardation in girls and its global frequency is one in 9,000 girls”, according to Dr. Bruria Gideoni Ben-Zeev, Head of the Pediatric Neurological Unit and Director of the National Rett Clinic at the Chaim Sheba Medical Center.

“Characteristics of the syndrome include normal development during the first months of life, accompanied by a deceleration on the normal increase in head circumference. Operational changes take place during the second or third year of the child’s life, including speech regression, loss of the use of the arms and repetitive hand motions, difficulty walking and sometimes also difficulty with earlier motor skills”.

### **What causes these difficulties?**

“The motor difficulties stem from a combination of a muscle tension disorder and motion disorders, which may become more severe with age. Epilepsy is frequent and may be difficult to control, as well as sleep disorders, behavior disorders, disorders of the digestive system, breathing disorders and other changes in the autoimmune system. One of the most common characteristics among Rett children is eye contact which is unique and may have functional meaning, as well as a surprising ability to learn if you “reach” them through the correct channels.

“To date, more than 100 girls and three boys have been diagnosed in Israel. In most cases, the cause is mutation of the MECP2 gene, which was identified in 1999 as the cause of the disease. Because this is a dominant gene on the X chromosome, one dose of the defective gene is enough to cause clinical manifestation, thus that manifestation occurs mainly in girls”.

### **And what happens in the boys?**

“Most of the boys either die in utero or suffer from much more severe illness which is not identified as typical Rett Syndrome. Genetic testing for Rett Syndrome is done at the Sheba Medical Center, but unfortunately it is not covered by National Health Care. There are quite a few different mutations and sometimes the effects of changes that take place in the gene are not clear. Thus, throughout the world tests during pregnancy are not customarily performed unless there is a previous case in the family. When a child in the family is found to have a mutation, prenatal testing for the mutation should be done in any subsequent pregnancy because of the 1% frequency of familial cases. Cases such as this have been identified here and around the world, thus preventing the birth of another ill child”.

### **Has the identification of the causal gene been helpful in any way?**

“Of course. Identification of the gene that is responsible for the syndrome has been helpful not only on the diagnostic level regarding the affected girls and their families, it has also brought about great momentum in research, in an attempt to find ways to treat the syndrome and possibly even cure it”.