

Dreams Never Dreamed

A Mother's Promise That Transformed Her Son's
Breakthrough into a Beacon of Hope





Kalman Samuels

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The Toby Press

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The Toby Press LLC
POB 8531, New Milford, CT 06776-8531, USA
& POB 2455, London W1A 5WY, England
www.tobypress.com

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ISBN 978-1-59264-525-1, *paperback*

A CIP catalogue record for this title is
available from the British Library

Printed and bound in the United States

*Dedicated
to my dear wife and life partner Malki*

to our beloved children

Nechama

Yossi

Yochanan & Michalli

Avi & Debbie

Simcha & Yocheved

Shlomo & Orit

Sara

and to our delightful grandchildren

*You are G-d's precious gifts to me
and a boundless source of love and care
for Yossi*



Contents

Preface xi

1. Early Days 1
2. The Road to Jerusalem 9
3. My New World 23
4. Matchmaker 28
5. In Silence and Darkness 34
6. New York 42
7. By His Own Yardstick 51
8. The Pact 59
9. Medics, Mystics, and Mealtimes 65
10. The Letter from Dr. H. 74
11. Coming Home 84
12. A Seat at the Table 93

13. Payback Time 100
14. Settling In 102
15. Parallel Lives 109
16. In Search of Payback 115
17. Into the Legal Labyrinth 122
18. Goliath Stumbles 131
19. Diamonds Are Forever 138
20. Peace of Mind 146
21. Justice, Law, and the Daylight Between 149
22. Opening Doors 156
23. Intestinal Fortitude 162
24. Respite, Despite... 169
25. I Want to Close Down Shalva 173
26. Growing Up with Yossi 180
27. The Wachsmans 183
28. "It's Obvious, Kalman" 189
29. Beit Nachshon 196
30. Me and My Mommy 204
31. A Stressful Choice 212
32. Volvo 214
33. From Crayons to Perfumes 219
34. Forrest Gump 225
35. Pushing Forward, Expanding the Network 230

36. Stepping Up to the Professional Plate 240
37. Batting a Thousand 243
38. Bombs and Bombshells 248
39. Paying the Bill 255
40. The Exorbitant Price of Free Land 274
41. Back into the Legal Labyrinth 267
42. Moving On 273
43. Jerusalem! Our Feet Stand within Your Gates 276
44. Bologna 281
45. Unforeseen Security 286
46. From Dentistry to Oral Hygiene 288
47. Of Sheep and Prophecy 295
48. Toward Opening 301
49. The Shalva Band – Ambassadors of Change 309
50. Inclusion and Reverse Inclusion 320
51. Of Yossi and Dreams 325

Acknowledgments 333

Glossary of Hebrew and Yiddish Words 335

Photographs 341



Preface

Writing a book that necessarily exposes much that is private to myself and to my family was not in my plans. As my son Yossi became well known, good friends urged me to share his story and, in doing so, raise awareness of the issues it embraces. But it was my beloved father, Norman Samuels, who finally convinced me. A man of few words, he was dying of cancer when he took my hand in his and said urgently: “Promise me that you’ll write that book!” Promise I did, and though it took many years, that promise is now fulfilled.

Much of what I have shared is based on my personal journals in which I recorded events, as well as my feelings and observations, in real time.

Some names have been changed to protect privacy and reputations.



Chapter 5

In Silence and Darkness

A downtown Jerusalem clinic was where it began. None of the clinic staff will talk about what happened there that day. It was October 16, 1977. Yossi, then two weeks short of his first birthday, remembers nothing of course. But every detail of that afternoon, now over forty years ago, is seared into the memory of my wife, Malki.

“I never liked the well-baby clinic,” she says. “Maybe it was intuition. It wasn’t that I knew anything could go wrong. After all, this was 1977. Information wasn’t out there, the way it is now. There were no PCs, no internet, no mobile phones, no social media. And anyway, it wasn’t for parents to second-guess doctors and nurses. It was a hot day and I was at the end of my third pregnancy. I thought about postponing the visit but decided I must go. I’d be having the new baby any day and then Yossi’s second immunization would be delayed for weeks. I slowly walked the few blocks to the local well-baby clinic and climbed the stairs carrying my beautiful little boy. The pediatrician, Dr. Neiman, ran the usual

checks – psychomotor, sight, hearing, weight, height. She entered Yossi’s developmental milestones on her medical chart and told me he was doing well. Then the nurse sat my alert and smiley baby in my lap and gave him the shot.”

On that hot October afternoon, Israel’s health authorities had already known for almost five months that the vaccine batch they were using for the routine triple immunization against diphtheria, pertussis, and tetanus (DPT) was dangerously flawed.

“I took Yossi home and followed the instructions they’d given me at the clinic,” Malki recounts. “I bathed him, gave him baby paracetamol, and let him sleep. The moment he woke, I knew my baby was gone. He looked up at me with shiny eyes as if to say: ‘What have you done to me?’”

On that terrifying afternoon, when Malki picked up our beautiful little boy from his nap and saw he was “gone,” she had no way of reaching me. She called the clinic and was told not to worry. There was no phone in the yeshiva where I was engrossed in my studies, and I knew nothing until I got home at about 7:15 p.m. As I walked in the door, my panic-stricken wife propelled me into the children’s room. Yossi was in his crib, lying on his back. “Look at him! Look!” she cried. “Look at his eyes! It’s not my Yossi! It isn’t him! He’s not responding! Something’s terribly wrong!”

I picked Yossi up and he smiled painfully. I looked at his eyes and saw that there was indeed something amiss. His eyes were glassy with a shimmer that had not been there that morning when I left him. Malki wanted to call the pediatrician immediately. “No,” I told her. “It’s probably just a cold. We’ll let the baby sleep and call the pediatrician in the morning, if we need her.”

The next morning Yossi was worse. He was running a fever, his nostrils were blocked, and he was clearly in distress. We called our pediatrician, Dr. Kanner, who was well qualified and affiliated with Jerusalem’s Shaare Zedek Hospital. Arriving at the house a few hours later, she examined Yossi thoroughly, diagnosed a viral

infection, and prescribed paracetamol and fluids. Several days later, with no improvement in Yossi, she decided it was time for antibiotics. Diligently we dosed him, but as time passed not only was he getting worse, he also began making sudden jerky movements.

We didn't know what to do for our baby and felt utterly helpless. Malki could take no more. I called the doctor demanding that she come that very day to see the child again. She came in the evening at 9:00 p.m., after her day at the hospital. This time, she was visibly concerned. She asked to use our phone and spoke to Dr. H., a leading neurologist at a Jerusalem hospital. We were told to be at her clinic first thing next morning for a full examination. Clearly, this was something more than a virus, but who were we, as young parents, to be told what it was? Obediently, we brought Yossi to Dr. H. as directed, at nine the next morning.

With a medical assistant present, Dr. H. spent five minutes examining Yossi. She then sat down and slowly spoke words we will never forget. "Did this child recently receive a DPT vaccination?" Her words hit us like a tidal wave. Malki and I looked at each other and said almost in unison, "Yes, he did, and that's when all this began."

Dr. H. said nothing but got up and left the office with her assistant. When she finally returned after what seemed an eternity, she handed us a sealed envelope and told us to wait down the hall for the eye specialist. In hindsight, it amazes me that we meekly heeded her without asking any questions, but she was a top neurologist and we were young parents. We made our way down the hall to wait for the doctor. He examined Yossi thoroughly, and when we asked him what he saw in Yossi's eyes, he didn't respond but rather wrote notes on Dr. H.'s piece of paper, resealed it in the envelope, and told us to return it to her.

After another long wait, Dr. H. called us in again. She read the ophthalmology notes and told us to come back two days later, on Sunday morning, for an EEG. We asked what was going on.

She said it was too early to tell. First we had to check the electrical activity in Yossi's brain.

Malki and I left the hospital distraught. We'd been told nothing about what was wrong with Yossi, and we felt bypassed and powerless. In retrospect, our treatment seems unreal, but this was Israel in 1977. We got through the two days, playing with our daughter and comforting our son, until we were due back at the hospital. Early Sunday morning we brought Yossi in for his EEG.

Dr. H. said she saw nothing amiss on the scan and that his brain activity was normal. "Yossi's fine," she said. "Come back in six weeks for a further check."

But Yossi was not fine. The movement in his eyes became far more acute, with his eyeballs seeming to roll in his head. He was making frequent, sharp, and sudden jerks, throwing his head forward and backward, knocking it against whatever was in range. None of the doctors had told us Yossi was suffering from convulsions, and certainly no one notified us that the pertussis vaccination could in rare instances cause them and to be alert for that.

We called Dr. Kanner to update her. Hesitantly, she told us that she knew of another baby recently injured by the DPT vaccine. That incident had occurred in June, four months before Yossi had received the vaccine, and that baby had died.

We called in a big-name physician for a home visit. After he examined Yossi, we told him about the triple vaccine and asked him what he thought. His words still ring in my ears: "Sometimes, at the age of one year, children become retarded. May I now use your phone to contact my next patient?" And that was it. He rushed to another house call, only stopping long enough to be paid.

Our feelings of fear and frustration were boundless.

On December 3, some seven weeks after Yossi's vaccination, Malki gave birth to Yochanan, who weighed in at over ten pounds. With all the joy our new baby brought us, life was very difficult.

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Our eldest child, Nechama, was two and a half years old. Yossi continued convulsing and his health continued to deteriorate. I recall taking him to visit two elderly Canadian aunts at a Jerusalem hotel. One of them was holding him when he gave a sudden and immense jerk, arching backward and banging his head on the lobby's glass table. I still had no idea that these jerks were called convulsions.

I took Yossi back to Dr. H. in late December 1977 for his six-week follow-up. She examined him briefly, then gave him a large ball to hold and spent a few more minutes with him. Then she said: "He seems fine. There's nothing more I can do at this time. He'll be OK." I asked when we should next bring him to see her. "No need to come again," she said. "He'll be OK."

Either I was a total fool or so anxious to believe my child was well that I suspended common sense. I came home upbeat with the wonderful news that Dr. H. said Yossi was fine. Malki saw things more clearly. Holding our little boy tightly, she cried: "Kalman, this child is fine? This child is healthy? What kind of doctor is she? She's not blind and she's not stupid – so tell me, what is she talking about? Why isn't she telling us what's wrong with him?"

Dr. H. had given me a sense that the situation would resolve itself. Clearly, that was what I needed to believe at the time.

Today I am wiser.

Today, I know that her behavior was collusion, and that she, with many of her colleagues, turned her back on both her medical ethics and her sense of human decency. And today I also know that Yossi was one of many children damaged by the faulty DPT vaccine during the six months it was administered, killing some and putting others into a lifelong vegetative state.

On December 5, 1977, seven weeks after Yossi had been irreversibly injured, the government ordered the country's well-baby clinics to halt all DTP vaccinations. They initially admitted that six

children had been harmed, later expanding that figure to eleven and then twelve, among whom they did not number our son.

Two weeks later, on December 19, an almost unimaginably long interval in today's world of instant news, the story hit the Israeli press. The headline in the daily *Maariv* paper read:

**Triple Vaccine Halted!
Six Severe Reactions in Six Months**

The supervisor of Israel's well-baby clinics has announced that, two weeks ago, all clinics countrywide were ordered to cease administration of the DPT vaccine. Well-baby clinic directors were instructed to return all unused DPT vaccines and not to administer any part of the triple vaccine until further notice. The DPT has been stopped because of six severely negative reactions, two of them resulting in death. The matter is being thoroughly investigated.

According to Health Ministry Director-General, Dr. Tibor Schwartz, the problem is in the pertussis component. "We have decided to bring in a new vaccine batch so that children won't go unvaccinated," he said. "We are bringing it in from Europe. We won't stop the vaccination program. Our statistics show the same results as European studies, with a problematic reaction in one out of 50,000 cases, with some countries having a lower percentage of incidents, namely one problematic reaction out of 100,000 cases. This is an acceptable and known risk. Six severe reactions in six months are unusual and unacceptable. We don't know what occurred and if there is, in fact, a link between the DPT and the negative outcomes. We have our suspicions, but no clear answers, as yet.

Two months after that, on February 6, 1978, Israel's largest-circulation daily, *Yediot Aharonot*, announced:

Vaccine to Be Restored: “It’s Safe”

The triple vaccine has been declared safe and will be resumed within the next two weeks. In 11 cases of severe complications following DPT vaccination, investigation has revealed that the pertussis component was the culprit. Three of the 11 affected infants died. No direct causal relationship has been found between the vaccine and the complications. Despite this, the Health Ministry decided on its withdrawal because of the Ministry’s concern for public well-being.

A comparison between the number of injuries in Israel from this batch and those outside [from other batches] showed that serious complications in Israel were five times more frequent than in the UK. A British batch is now being used in Israel. A large amount of this vaccine arrived here during the past two weeks and is now being checked.

I didn’t see these newspaper accounts at that time. We were totally occupied with Yossi. He was not “OK,” as Dr. H. had assured us he would be, and his problems, rather than passing, continued to become more and more severe. Our lives revolved around our injured child, with never a quiet or tranquil moment, as we tried to protect him from himself and from others. Worse than all of this was seeing him desolate, locked in his own world, a small, lonely being with whom we couldn’t communicate.

Malki cried a lot. She saw her child was in pain and didn’t know how to help him. That, for her, was the most difficult thing in the world: to know your child needs help, is crying out for help, and you cannot provide it.

We visited many doctors. Those lower down the food chain had no idea what was wrong. Those above them knew only too well, but no one would talk about it. It was clear that an order had been issued by someone powerful and highly placed

to conceal these vaccine-related injuries, thus sealing all medical doors tight.

Meanwhile, Yossi's situation continued to deteriorate. His eyes still rolled, and he was unable to focus. His nose, swollen and blocked from his falls and knocks received during convulsions, defied all efforts to clear it and he could breathe only through his mouth. He was beginning to walk, but his gait was awkward and he fell often. Unable to see, Yossi's world was restricted to what he could touch.

Using the very limited sensory information available to him, Yossi was desperately trying to make sense of his universe. And we, with no experience but with all the love in the world, tried to help our child with his extraordinary challenges.

Yossi was a good teacher. Startled if approached or touched too suddenly, he taught us that in his world, things appear out of nowhere and disappear into nowhere. He showed us that he needed gentle cues before being approached so that he could gather information and prepare himself to make his world intelligible and safe. He needed routine and, no less important, stimulation.

Desperate to find a way to help our child, we continued trudging from doctor to doctor – never receiving an explanation, a diagnosis, or any concrete help. When my father's brother Herschel urged us, late that year, to come to New York and meet expert doctors who would speak with us, we were out of other options. Uncle Herschel, thirteen years younger than my father and a brilliant man with a photographic memory, was at the time the co-director of orthopedics at the Maimonides Medical Center in Brooklyn.

And so we made a painful decision: we would take Uncle Herschel up on his suggestion in the hope that we would find out what exactly was wrong with Yossi and in turn learn how we could best help him. Nechama was three, Yossi was two, Yochanan was just over a year, and unbeknownst to us when we left Israel, Malki was pregnant and Avi was on the way.